LOCATING INFORMATION ON DEVELOPMENTAL DISABILITIES USING NLM RESOURCES

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AGENDA

- Who we are
- Basics about developmental disabilities
- Evaluating websites
- NLM, NIH, and other resources
- Concerns and issues
- Interaction and language
- Library programs and services

WHO ARE WE?

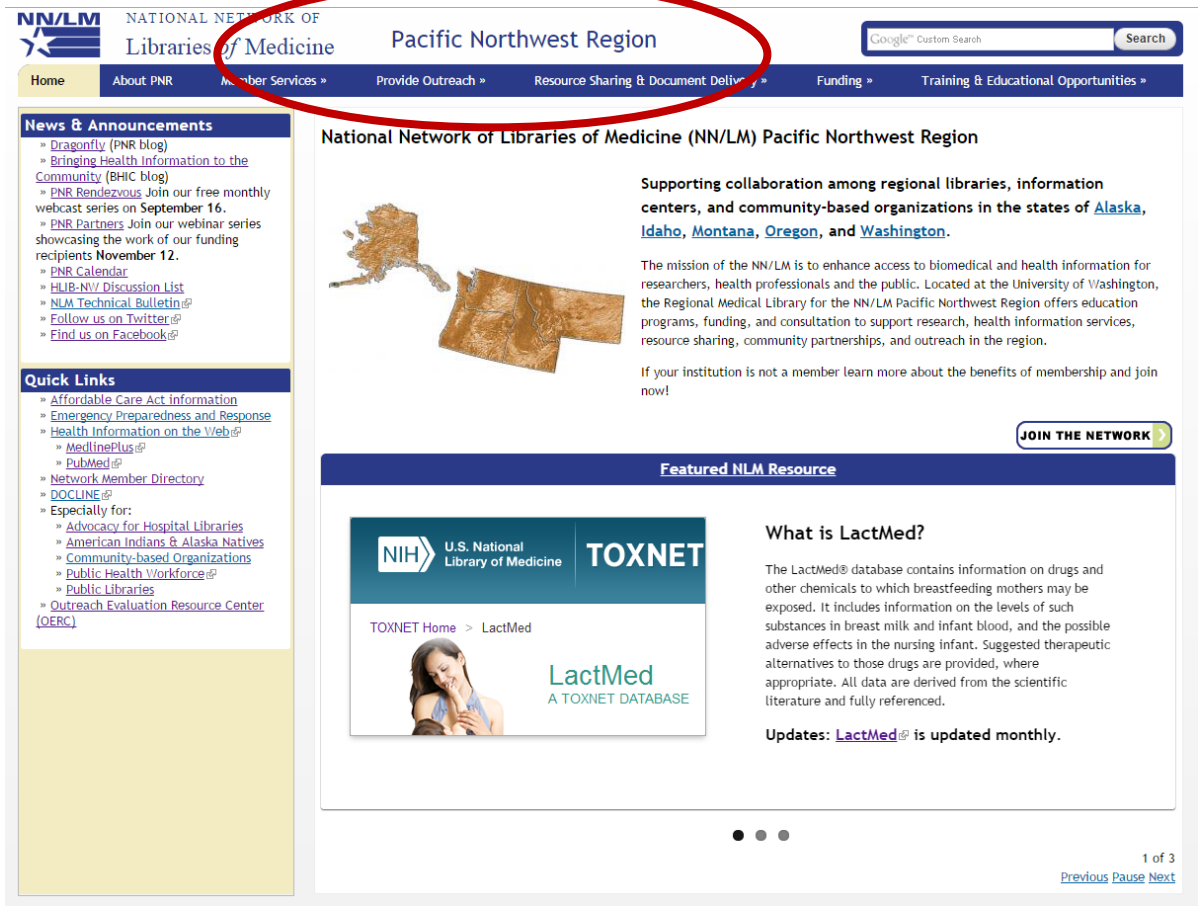
NIH

NLM

NN/LM

What's the difference?

National Network of Libraries of Medicine



NN/LM NATIONAL NETWORK OF Libraries *of* Medicine — Pacific Northwest Region

NN/LM NATIONAL NETWORK OF Libraries *of* Medicine — Pacific Northwest Region

Google™ Custom Search — Search

Home | About PNR | Member Services » | Provide Outreach » | Resource Sharing & Document Delivery » | Funding » | Training & Educational Opportunities »

News & Announcements

- » Dragonfly (PNR blog)
- » Bringing Health Information to the Community (BHIC blog)
- » PNR Rendezvous Join our free monthly webcast series on **September 16.**
- » PNR Partners Join our webinar series showcasing the work of our funding recipients **September 10.**
- » PNR Calendar
- » HLIB-NW Discussion List
- » NLM Technical Bulletin
- » Follow us on Twitter
- » Find us on Facebook

National Network of Libraries of Medicine (NN/LM) Pacific Northwest Region

MEMBERSHIP- FREE

Supporting collaboration among regional libraries, information centers, and community-based organizations in the states of Alaska, Idaho, Montana, Oregon, and Washington.

The n… resea… the R… progr… resou…

If you… now!

DOCLINE

Three times a year, we … Pacific Time and last on…

Wednesday, September …

Home

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- Provide Outreach
- What NN/LM PNR Can Do For You
- What You Can Do For Others

Provide Outreach

OUTREACH & TRAINING

The NN/LM PNR equips and encourages Network members to extend their services and expertise to groups, agencies, and institutions beyond their traditional reach. By developing and expanding collaborations, the Network works to accomplish its primary goals-to improve the public's access to information to enable them to make informed decisions about their health, and to provide all health professionals with equal access to biomedical information.

Back to top

What NN/LM PNR Can Do For You

- Provide consultation and support for you to partner and collaborate with agencies in your community to provide health information services. Assist with planning and evaluating outreach.
- Provide training and professional development opportunities so you can update your skills or learn new techniques in providing health information. We use the train-the-trainer model to equip you to train your staff or clients regarding health information issues. Training sessions cover a range of topics - from utilizing National Library of Medicine resources, evaluating health information for quality, to using evaluation methods to measure your impact within your organization.
  - Training Resources you can use: including lession plans, toolkits, brochures.
  - Trainers from the National Training Center and Clearininghouse come to the Pacific Northwest on a regular basis to offer in-depth training. The schedule of these classes along with classes to request from PNR staff and many of our class materials is available here.
  - Here is a calendar of events listing where regional NN/LM staff will be offering training sessions or staffing exhibits throughout the region.
- Provide funding for health information outreach projects in your community. To find out about funding opportunities visit this page, which

Home

Funding Opportunities and Resources

FUNDING

Table of Contents [hide]

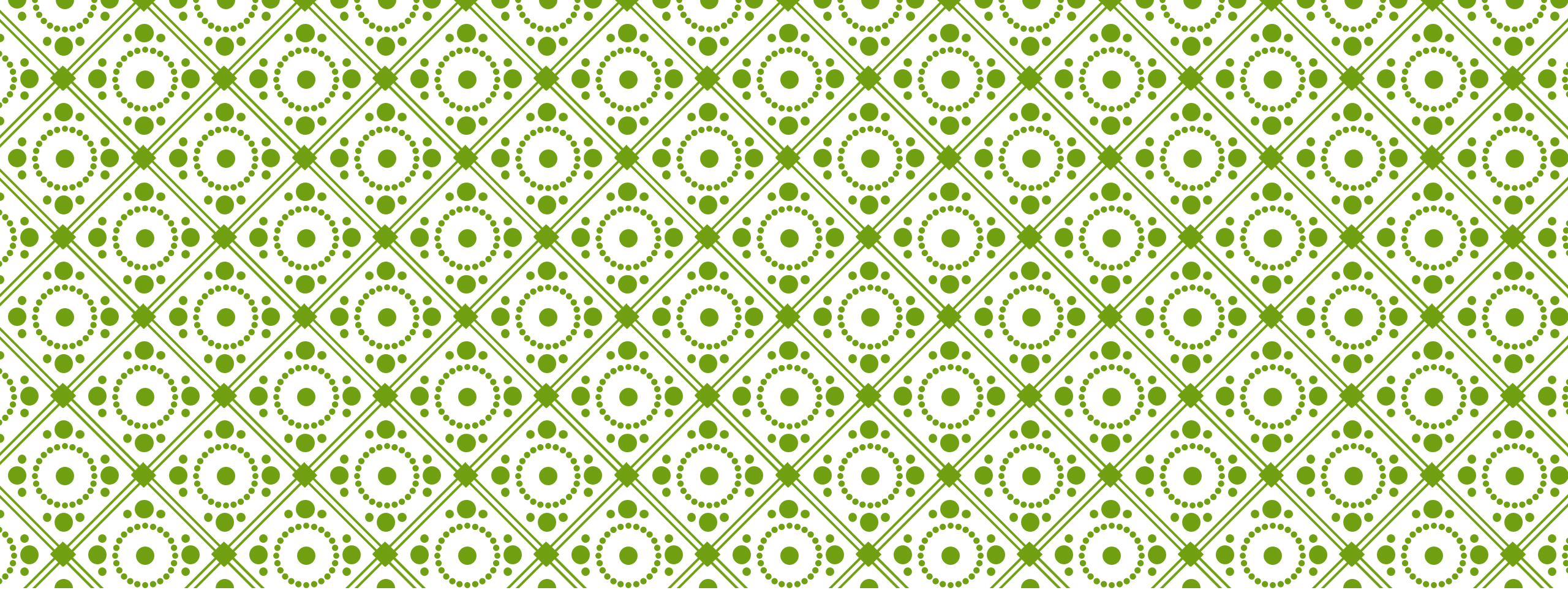
- PNR Awards 2011 - 2016
- PNR Projects Funded 2006 - 2011
- PNR Projects Funded 2011 - 2016
- Grants and Support from the National Library of Medicine

Back to top

PNR Awards 2011 - 2016

Each year, the PNR funds subcontracts and awards to support n… members and encourage outreach activities aligned with the NN/LM mission.

Available Awards	Purpose	Funding	Submit Intent to Apply By	Application Deadlines
Express Outreach	To improve use of quality online health information resources by priority populations, facilitate improved health literacy and to promote awareness and use of the products and services of the NLM and the NN/LM.	Up to $15,000	N/A	Currently Closed
Medical Library Pilot Project	To recognize and support emerging roles of the information professional through pilot or demonstration projects that explore or demonstrate innovative roles within their institution.	Up to $15,000	N/A	Currently Closed
Regional Symposia	To support Network members in planning and hosting regional symposia about issues and priorities of the NN/LM PNR Program.	Up to $10,000	N/A	Currently Closed
Technology …	To enhance the capacity of a library or community organization to offer electronic health information services by supporting the purchase,	Up to $10,000	N/A	Currently …



BASIC INFORMATION

regarding developmental disabilities

DEFINITION OF DEVELOPMENTAL DISABILITIES

CDC definition:

"Developmental disabilities are a group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime."

CDC Developmental Disabilities section: http://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html

CAUSES/ RISK FACTORS

Most conditions caused by complex mix of factors:

- Genetic or chromosome abnormalities, causing conditions such as Down syndrome and Rett syndrome
- Certain viral infections during pregnancy
- Exposure of the mother or child to high levels of environmental toxins, such as lead
- Parental health and behaviors (such as smoking and drinking) during pregnancy
- Birth complications
- Preterm birth

WHO IS AFFECTED

- All ethnic, racial and socioeconomic groups
- 1 in 6, or about 15% of U.S. children aged 3 through 17 years, have one or more developmental disabilities or delays (2006-2008 survey)

STATISTICS

The prevalence of any DD (1997–2008) - 13.87%

- Prevalence of learning disabilities - 7.66%
- Prevalence of attention deficit hyperactivity disorder (ADHD) - 6.69%
- Prevalence of other developmental delay - 3.65%
- Prevalence of Autism - 0.47%

WHAT DOES THIS MEAN FOR INDIVIDUALS AND FAMILIES?

- Limited access to treatment and services
- Limited knowledge of and/or navigating social services, educational assistance, medical needs
- Extra effort and time to advocate and assist
- Job limitations
- Economic effects
- Cultural, language, literacy factors have additional impact
- Ethnic and racial disparities
- Affects whole family

HEALTH DISPARITIES

- Access to services
- Healthcare costs
- Knowledge/understanding basics of health
- Knowledge/understanding of treatments, procedures, aftercare
- Less advocacy
- Knowledge/understanding by health care industry
- Fewer options
- More complex care
- Medicaid
- Less research available

PROGRESS NEEDED:

- More awareness
- More services
- Better understanding of medical and social aspects
- Risk factors
- Early interventions
- Assistance to families and individuals
- Acceptance in schools, employers, businesses, and society in general

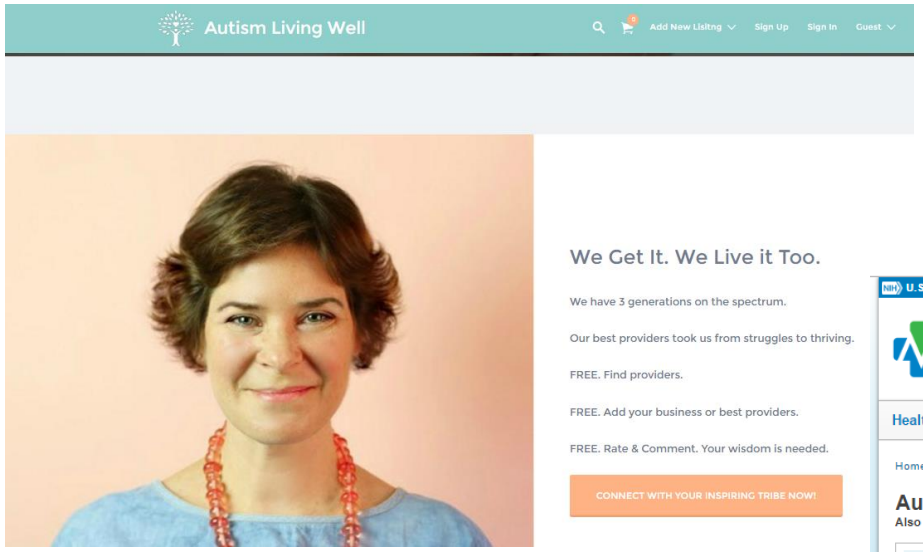
EVALUATING WEBSITES

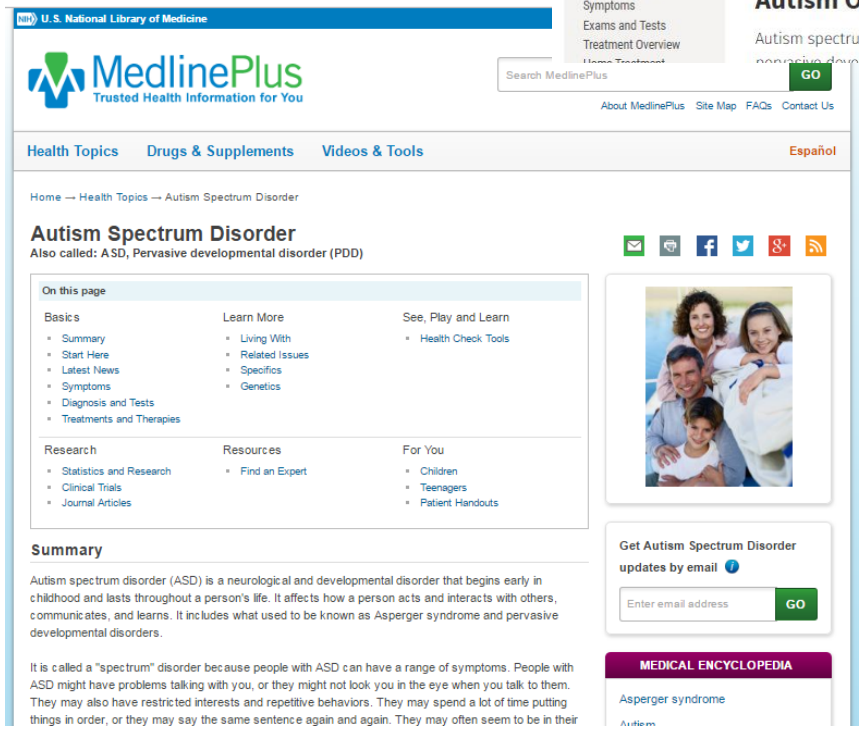
ABCs of website evaluation

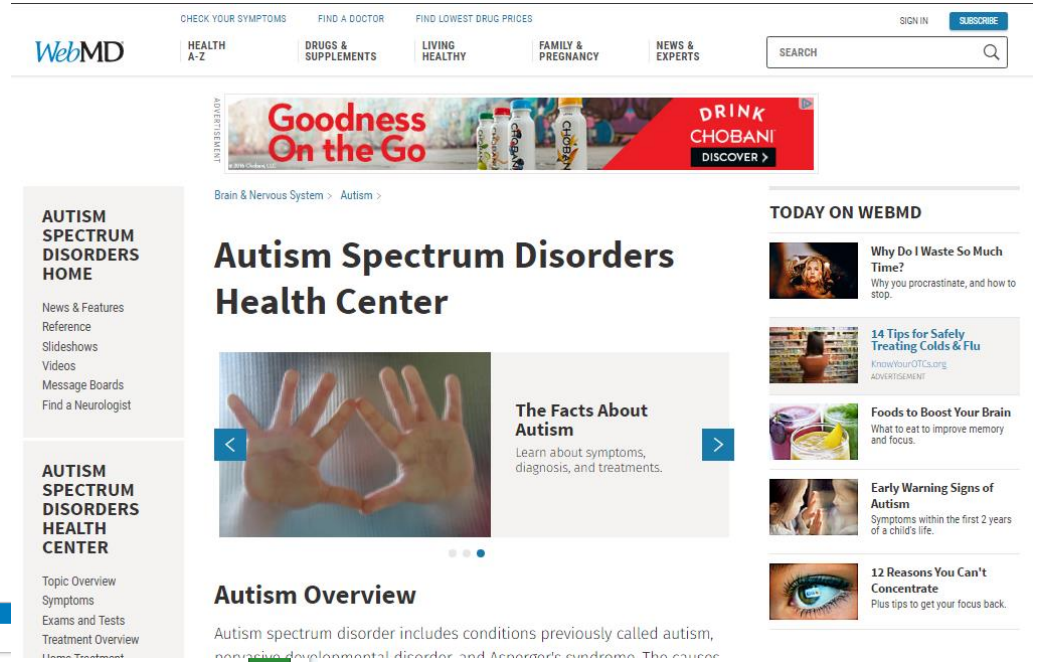
EVALUATING WEBSITES

- Accuracy
  - Based on sound medical research?
  - Can information be verified?
- Authority
  - Credentials of author
  - Contact information
  - Domain name: .edu, .org, .gov Versus .com, .net
- Bias/Objectivity
  - Advertising?
  - Sponsoring institution: pharmaceutical company? Non-profit?
- Currency
  - Last updated?
  - Links work?
- Coverage
  - Information complete?
  - Are sources provided?

EVALUATING WEBSITES

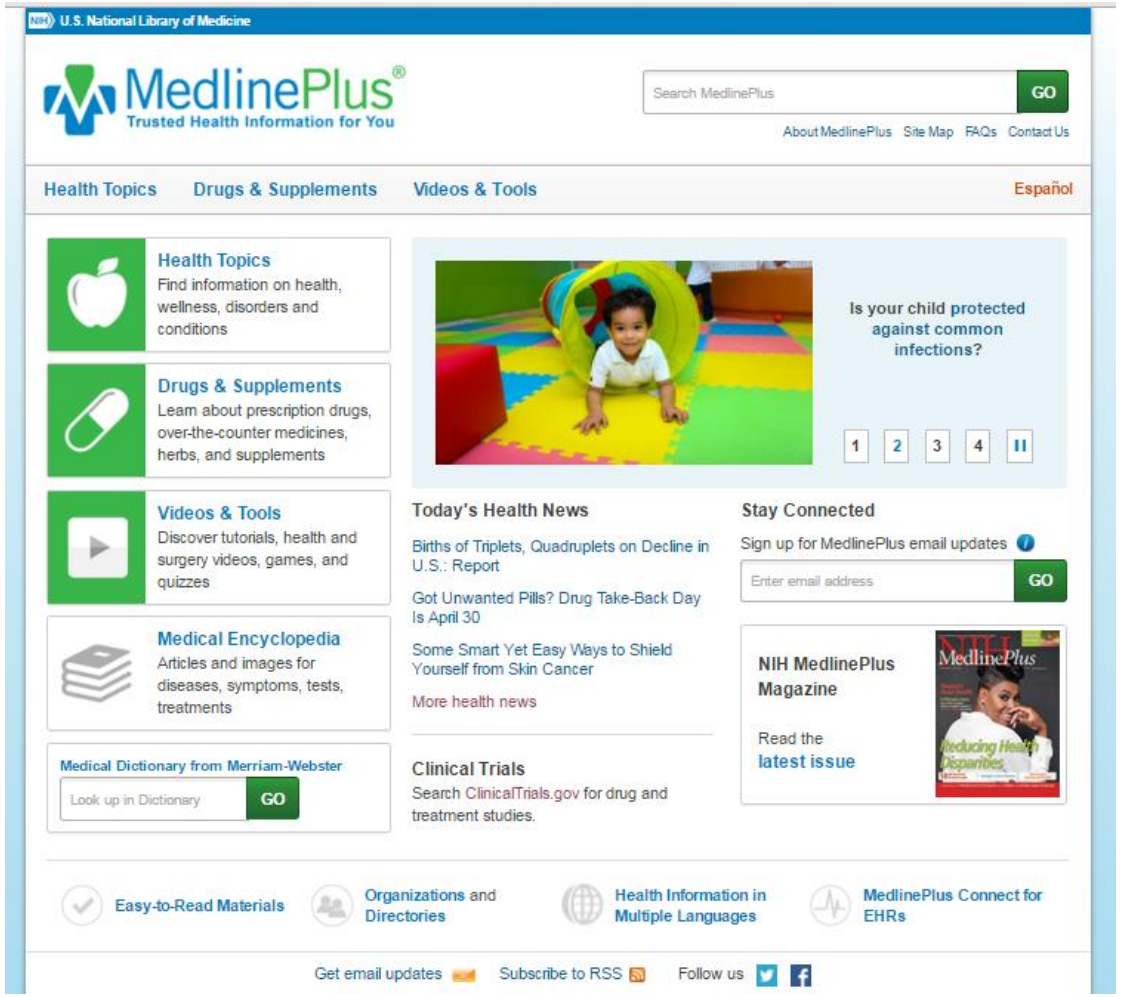


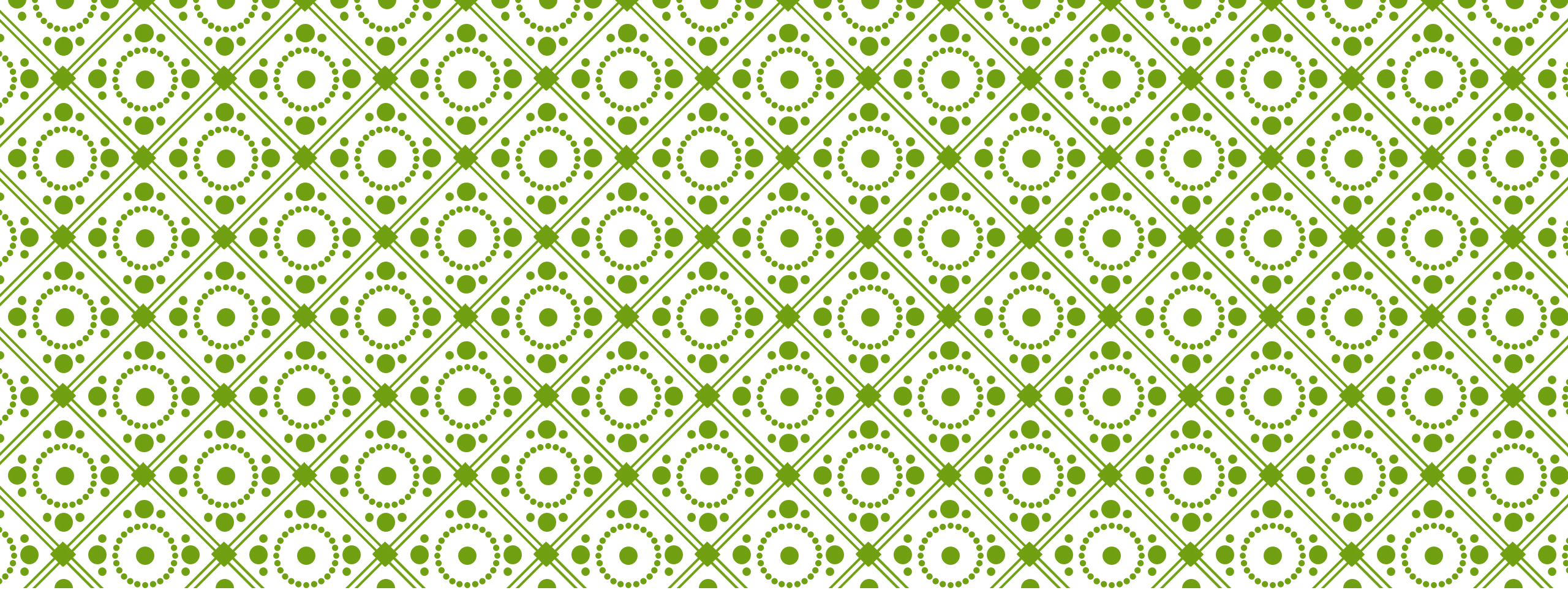




MEDLINEPLUS

HTTPS://WWW.NLM.NIH.GOV/MEDLINEPLUS/





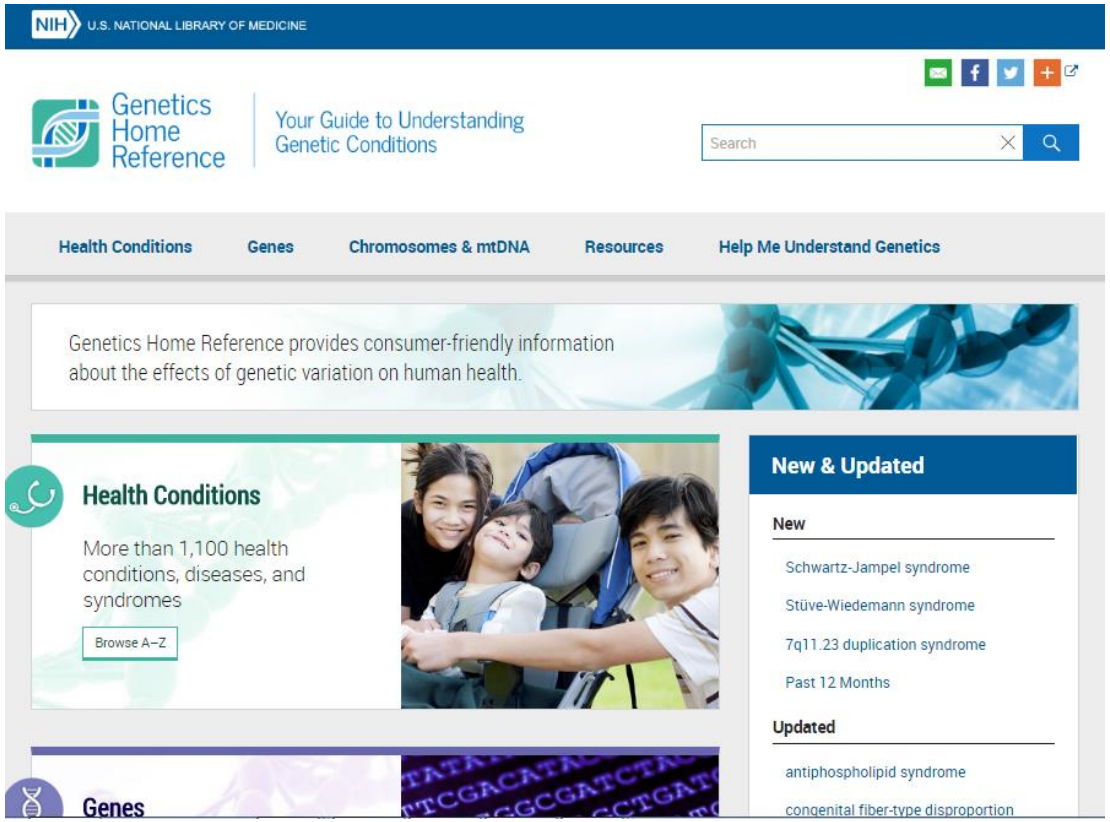
LOCATING INFORMATION USING NLM RESOURCES

and other resources

NLM RESOURCES

MedlinePlus

Genetics Home Reference

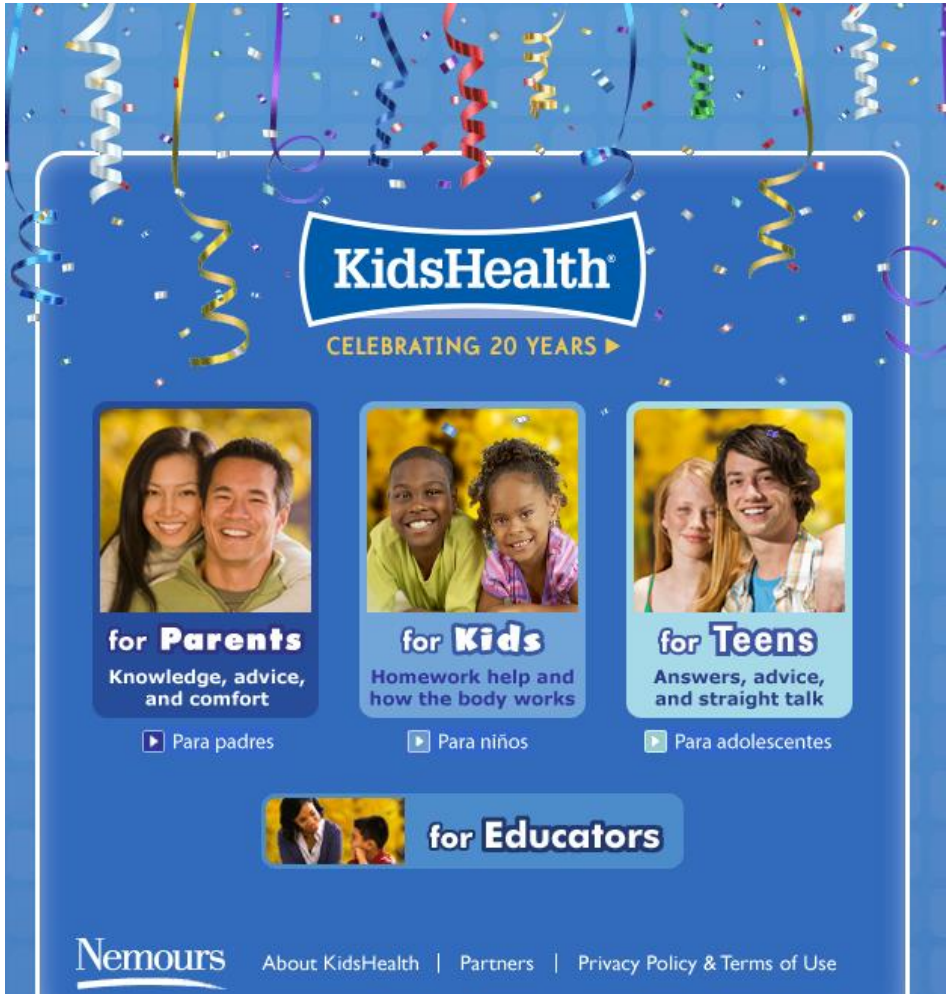


NIH EUNICE KENNEDY SHRIVER NATIONAL INSTITUTE OF CHILD HEALTH & HUMAN DEVELOPMENT (NICHD)

NIH NATIONAL INSTITUTE OF ARTHRITIS & MUSCULOSKELETAL & SKIN DISEASES (NIAMS)

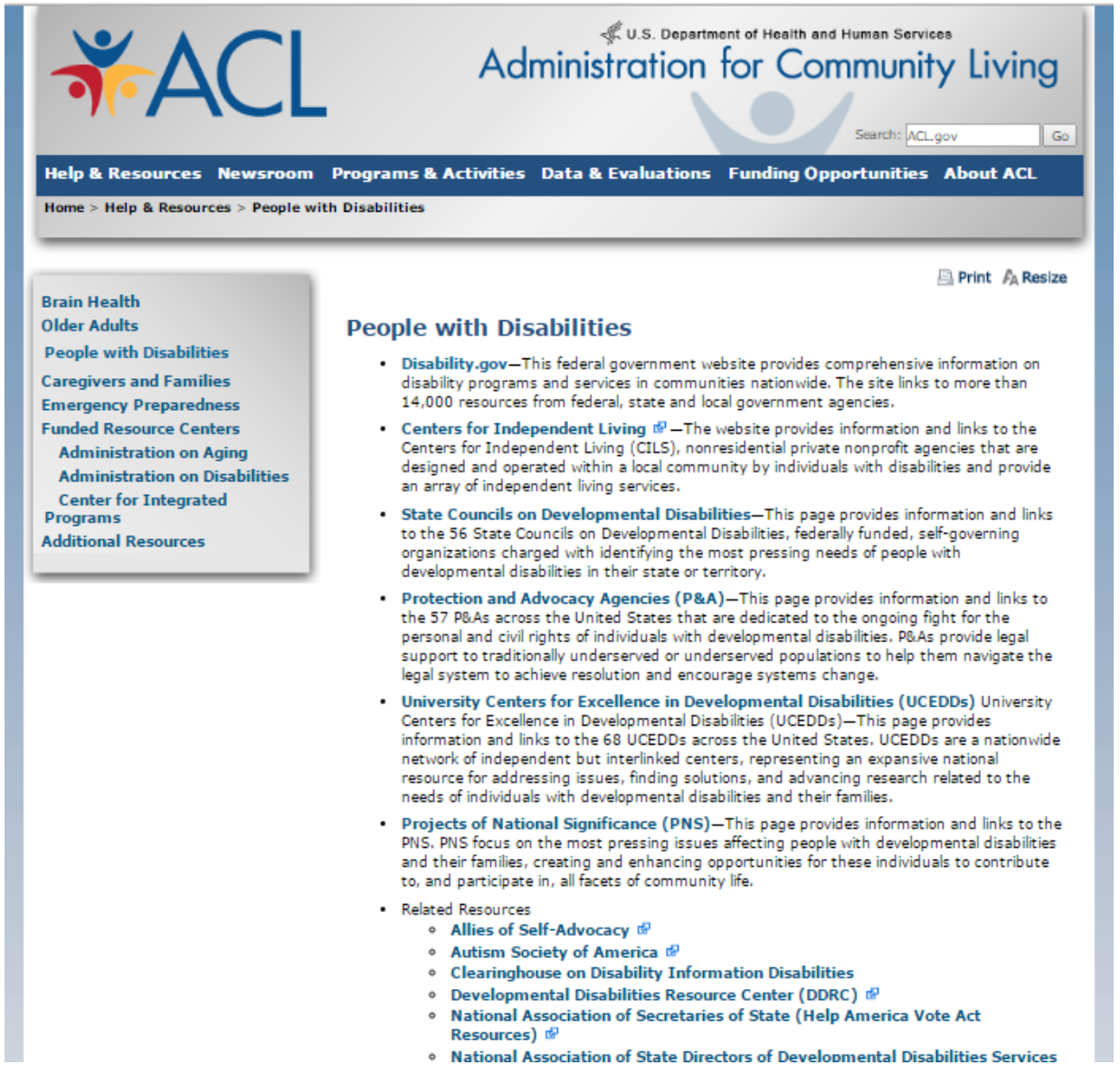
NIH NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE (NINDS)

KIDSHEALTH.ORG

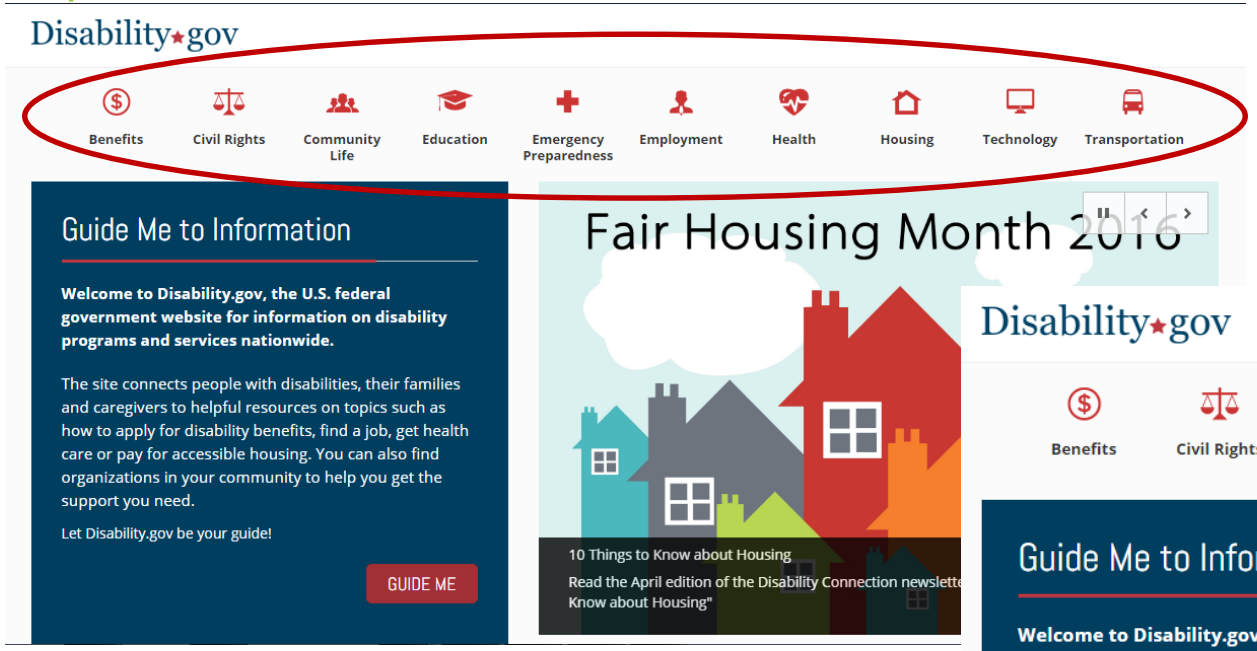


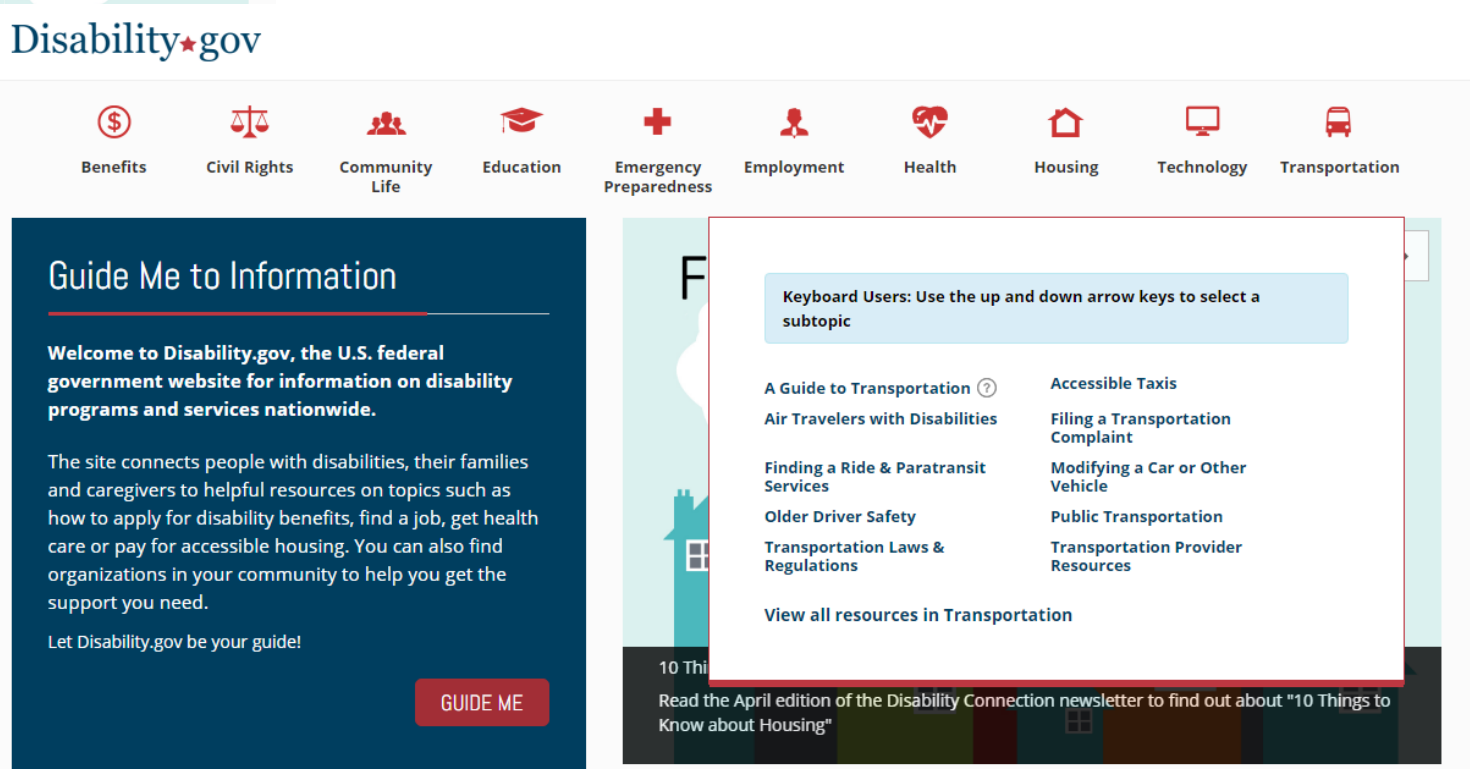
ACL.GOV

U.S. Department of Health and Human Services
Administration for Community Living
Search: ACL.gov Go
Help & Resources Newsroom Programs & Activities Data & Evaluations Funding Opportunities About ACL
Home
FEATURES
EJCC Spring Meeting
Brain Health Facts (PDF)
Older Americans Month
OAA Reauthorization
Why Community Living?
Strengthening Communities
Aging Programs
Developmental Disability Programs
AIDD Programs & Activities
AoA Programs & Activities
Learn About ACL Initiatives
Recent ACL Blogs (view all blog posts)
Moving the Boulder on Elder Justice: 5 Years of Collaboration (05/04/2016)
ACL and The Leadership Conference: This Autism Awareness Month, Let's Remember that our Movements are Interconnected (04/30/2016)
News and Information (view full listing)
Webinar - Getting the Word Out: Creating Compelling Communications for World Elder Abuse Awareness Day (05/04/2016)
Older Americans Act Reauthorization Signed into Law (04/19/2016)
March is National Nutrition Month (03/11/2016)


U.S. Department of Health and Human Services
Administration for Community Living
Search: ACL.gov Go
Help & Resources Newsroom Programs & Activities Data & Evaluations Funding Opportunities About ACL
Home > Help & Resources > People with Disabilities
Print Resize
Brain Health
Older Adults
People with Disabilities
Caregivers and Families
Emergency Preparedness
Funded Resource Centers
Administration on Aging
Administration on Disabilities
Center for Integrated Programs
Additional Resources
People with Disabilities
Disability.gov—This federal government website provides comprehensive information on disability programs and services in communities nationwide. The site links to more than 14,000 resources from federal, state and local government agencies.
Centers for Independent Living—The website provides information and links to the Centers for Independent Living (CILS), nonresidential private nonprofit agencies that are designed and operated within a local community by individuals with disabilities and provide an array of independent living services.
State Councils on Developmental Disabilities—This page provides information and links to the 56 State Councils on Developmental Disabilities, federally funded, self-governing organizations charged with identifying the most pressing needs of people with developmental disabilities in their state or territory.
Protection and Advocacy Agencies (P&A)—This page provides information and links to the 57 P&As across the United States that are dedicated to the ongoing fight for the personal and civil rights of individuals with developmental disabilities. P&As provide legal support to traditionally underserved or underserved populations to help them navigate the legal system to achieve resolution and encourage systems change.
University Centers for Excellence in Developmental Disabilities (UCEDDs) University Centers for Excellence in Developmental Disabilities (UCEDDs)—This page provides information and links to the 68 UCEDDs across the United States. UCEDDs are a nationwide network of independent but interlinked centers, representing an expansive national resource for addressing issues, finding solutions, and advancing research related to the needs of individuals with developmental disabilities and their families.
Projects of National Significance (PNS)—This page provides information and links to the PNS. PNS focus on the most pressing issues affecting people with developmental disabilities and their families, creating and enhancing opportunities for these individuals to contribute to, and participate in, all facets of community life.
Related Resources
Allies of Self-Advocacy
Autism Society of America
Clearinghouse on Disability Information Disabilities
Developmental Disabilities Resource Center (DDRC)
National Association of Secretaries of State (Help America Vote Act Resources)
National Association of State Directors of Developmental Disabilities Services

DISABILITY.GOV





CDC

Developmental disabilities are a group of conditions due to an impairment in physical, learning, language, or behavior areas. About one in six children in the U.S. have one or more developmental disabilities or other developmental delays.

BASICS
Milestones, screening, causes and risk factors, and living with a disability.

SPECIFIC CONDITIONS
Information about specific types of developmental disabilities.

RESEARCH & TRACKING
What we've learned and CDC's work.

ARTICLES
Scientific articles.

RESOURCE CENTER
Print or order free materials.

MULTIMEDIA & TOOLS
Videos, podcasts, and widgets.

LINKS TO OTHER WEBSITES
Links to information from other organizations.

ABOUT US
Overview of CDC's work.

DEVELOPMENTAL MILESTONES

Children reach milestones in how they play, learn, speak, behave, and move. CDC has checklists to help parents and others track a child's development.

More›

CDC Centers for Disease Control and Prevention
CDC 24/7: Saving Lives, Protecting People™

SEARCH

CDC A-Z INDEX

Developmental Disabilities

- Developmental Disabilities Homepage
- Facts
- Specific Conditions
- Research & Tracking
- Articles & Key Findings
- Free Materials
- Multimedia & Tools
- Links to Other Websites
- About Us

Information For...
- Media
- Policy Makers

Developmental Disabilities Homepage

Free Materials

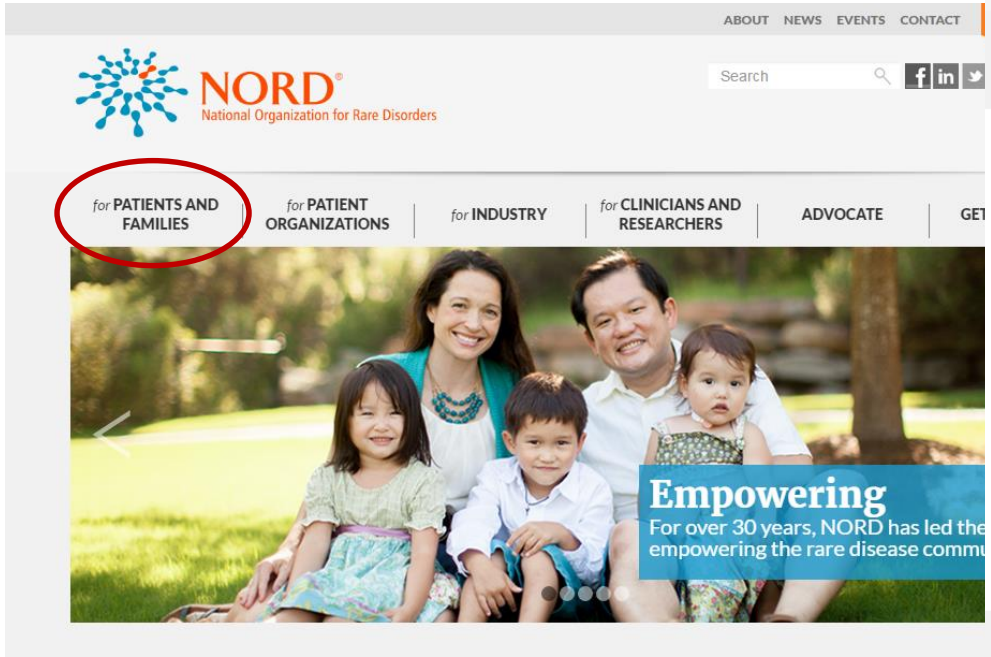
Language: English

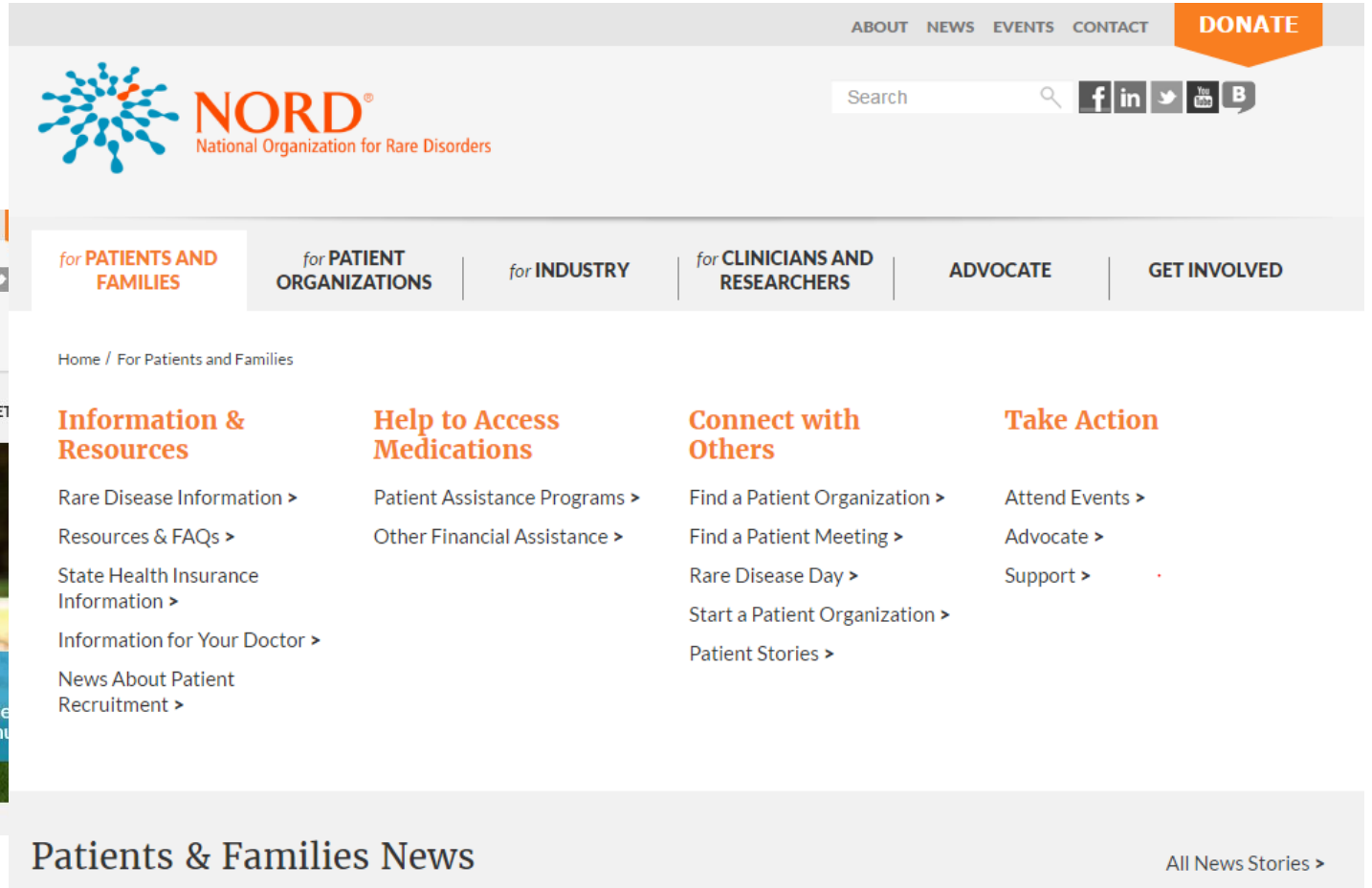
Attention-Deficit / Hyperactivity Disorder (ADHD)
People with ADHD have trouble paying attention, controlling impulsive behaviors, and in some cases, are overly active. CDC has materials for families.

Autism Spectrum Disorder (ASD)
Autism Spectrum Disorder (ASD) is a group of developmental disabilities that can cause significant social, communication and behavioral challenges. CDC has fact sheets, posters, a growth chart, and more in English and Spanish.

Fetal Alcohol Spectrum Disorders (FASDs)
FASDs are a group of conditions that can include physical problems and problems with behavior and learning. CDC has materials in English and Spanish for families, health professionals, and others on FASDs.

NORD


ABOUT NEWS EVENTS CONTACT
NORD®
National Organization for Rare Disorders
Search
for PATIENTS AND FAMILIES
for PATIENT ORGANIZATIONS
for INDUSTRY
for CLINICIANS AND RESEARCHERS
ADVOCATE
GET
Empowering
For over 30 years, NORD has led the
empowering the rare disease commu


ABOUT NEWS EVENTS CONTACT
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National Organization for Rare Disorders
Search
for PATIENTS AND FAMILIES
for PATIENT ORGANIZATIONS
for INDUSTRY
for CLINICIANS AND RESEARCHERS
ADVOCATE
GET INVOLVED
Home / For Patients and Families
Information & Resources
Rare Disease Information >
Resources & FAQs >
State Health Insurance Information >
Information for Your Doctor >
News About Patient Recruitment >
Help to Access Medications
Patient Assistance Programs >
Other Financial Assistance >
Connect with Others
Find a Patient Organization >
Find a Patient Meeting >
Rare Disease Day >
Start a Patient Organization >
Patient Stories >
Take Action
Attend Events >
Advocate >
Support >
Patients & Families News
All News Stories >

DRUG INFORMATION

DRUG INFORMATION

U.S. National Library of Medicine

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Health Topics | Drugs & Supplements | Videos & Tools | Español

Home → Drugs, Herbs and Supplements

Drugs, Herbs and Supplements

Drugs

Learn about your prescription drugs and over-the-counter medicines. Includes side effects, dosage, special precautions, and more.

Browse by generic or brand name:

A B C D E F G H I J K L M N O P Q R S T

U V W X Y Z 0-9

For FDA approved labels included in drug packages, see DailyMed.

Herbs and Supplements

Browse dietary supplements and herbal remedies to learn about their effectiveness, usual dosage, and drug interactions.

All herbs and supplements

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Related Topics

- HIV/AIDS Medicines
- Antibiotics
- Antidepressants
- Blood Pressure Medicines
- Blood Thinners
- Cancer Alternative Therapies
- Cancer Chemotherapy
- Cold and Cough Medicines
- Complementary and Alternative Medicine
- Diabetes Medicines
- Dietary Supplements
- Drug Safety

Home → Drugs, Herbs and Supplements → Sertraline

Sertraline

pronounced as (ser' tra leen)

- Why is this medication prescribed?
- How should this medicine be used?
- Other uses for this medicine
- What special precautions should I follow?
- What special dietary instructions should I follow?
- What should I do if I forget a dose?
- What side effects can this medication cause?
- What should I know about storage and disposal of this medication?
- In case of emergency/overdose
- What other information should I know?
- Brand names

IMPORTANT WARNING:

A small number of children, teenagers, and young adults (up to 24 years of age) who took antidepressants ('mood elevators') such as sertraline during clinical studies became suicidal (thinking about harming or killing oneself or planning or trying to do so). Children, teenagers, and young adults who take antidepressants to treat depression or other mental illnesses may be more likely to become suicidal than children, teenagers, and young adults who do not take antidepressants to treat these conditions. However, experts are not sure about how great this risk is and how much it should be considered in deciding whether a child or teenager should take an antidepressant.

You should know that your mental health may change in unexpected ways when you take sertraline or other antidepressants even if you are an adult over 24 years of age. You may become suicidal, especially at the beginning of your treatment and any time that your dose is increased or decreased. You, your family, or your caregiver should call your doctor right away if you experience any of the following symptoms: new or worsening depression; thinking about harming or killing yourself, or planning or trying to do so; extreme worry; agitation; panic attacks; difficulty falling asleep or staying asleep; aggressive behavior; irritability; acting without thinking; severe restlessness; and frenzied abnormal excitement. Be sure that your family or caregiver knows which symptoms may be serious so they can call the doctor if you are unable to seek treatment on your own.

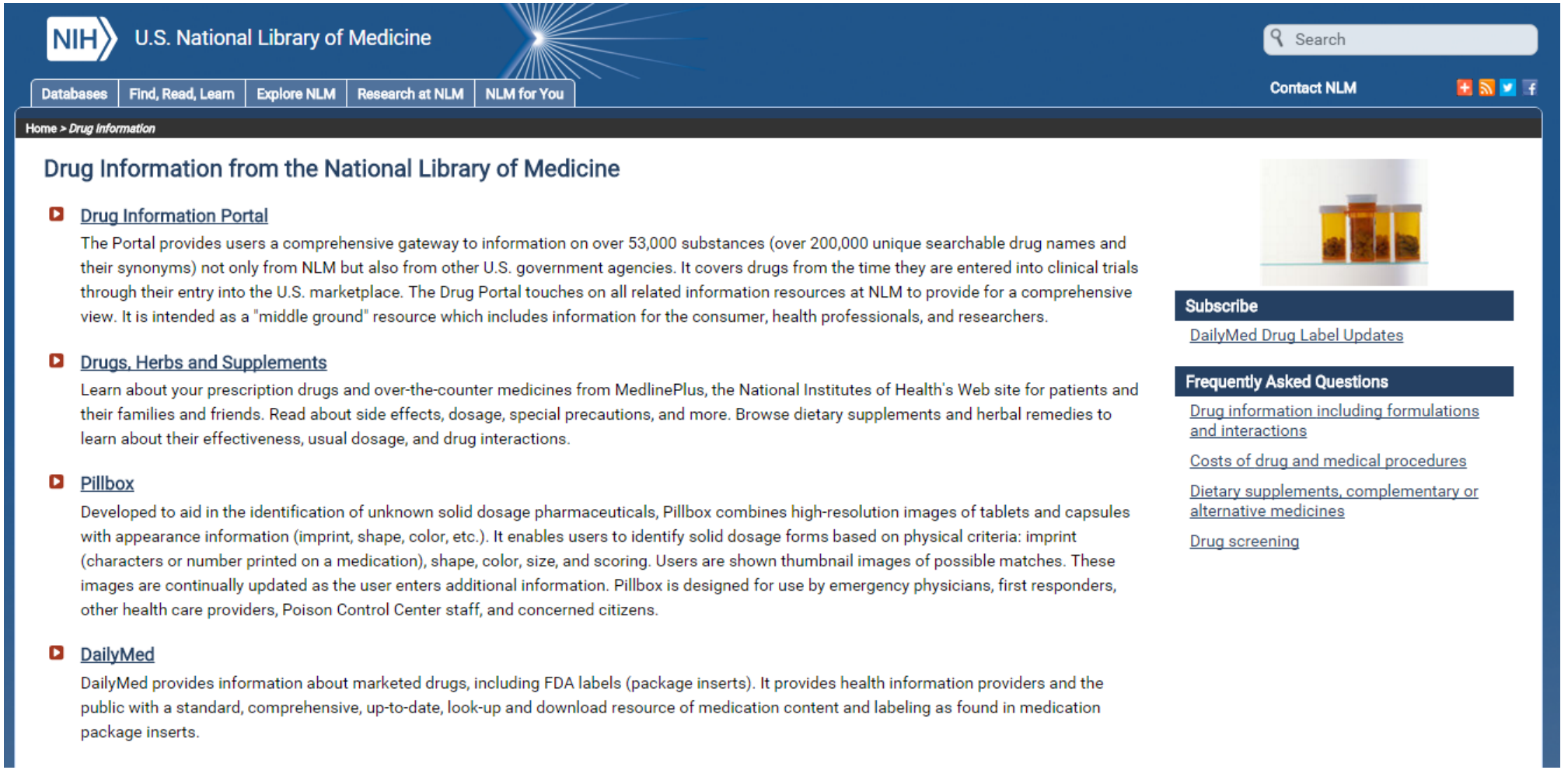
Your healthcare provider will want to see you often while you are taking sertraline, especially at the beginning of your treatment. Be sure to keep all appointments for office visits with your doctor.

The doctor or pharmacist will give you the manufacturer's patient information sheet (Medication Guide) when you begin treatment with sertraline. Read the information carefully and ask your doctor or pharmacist if you have any questions. You also can obtain the Medication Guide from the FDA website: http://www.fda.gov/Drugs/DrugSafety/InformationbyDrugClass/UCM096273.

No matter what your age, before you take an antidepressant, you, your parent, or your caregiver should talk to your doctor about the risks and benefits of treating your condition with an antidepressant or with other treatments. You should also talk about the risks and benefits of not treating your condition. You should know that having depression or another mental illness greatly increases the risk that you will become suicidal. This risk is higher if you or anyone in your family has or has ever had bipolar disorder (mood that changes from depressed to

DRUG INFORMATION PORTAL

NLM


NIH
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Search
Contact NLM
Databases
Find, Read, Learn
Explore NLM
Research at NLM
NLM for You
Home > Drug Information
Drug Information from the National Library of Medicine
Drug Information Portal
The Portal provides users a comprehensive gateway to information on over 53,000 substances (over 200,000 unique searchable drug names and their synonyms) not only from NLM but also from other U.S. government agencies. It covers drugs from the time they are entered into clinical trials through their entry into the U.S. marketplace. The Drug Portal touches on all related information resources at NLM to provide for a comprehensive view. It is intended as a "middle ground" resource which includes information for the consumer, health professionals, and researchers.
Drugs, Herbs and Supplements
Learn about your prescription drugs and over-the-counter medicines from MedlinePlus, the National Institutes of Health's Web site for patients and their families and friends. Read about side effects, dosage, special precautions, and more. Browse dietary supplements and herbal remedies to learn about their effectiveness, usual dosage, and drug interactions.
Pillbox
Developed to aid in the identification of unknown solid dosage pharmaceuticals, Pillbox combines high-resolution images of tablets and capsules with appearance information (imprint, shape, color, etc.). It enables users to identify solid dosage forms based on physical criteria: imprint (characters or number printed on a medication), shape, color, size, and scoring. Users are shown thumbnail images of possible matches. These images are continually updated as the user enters additional information. Pillbox is designed for use by emergency physicians, first responders, other health care providers, Poison Control Center staff, and concerned citizens.
DailyMed
DailyMed provides information about marketed drugs, including FDA labels (package inserts). It provides health information providers and the public with a standard, comprehensive, up-to-date, look-up and download resource of medication content and labeling as found in medication package inserts.
Subscribe
DailyMed Drug Label Updates
Frequently Asked Questions
Drug information including formulations and interactions
Costs of drug and medical procedures
Dietary supplements, complementary or alternative medicines
Drug screening

NIH NATIONAL CENTER FOR COMPLIMENTARY AND INTEGRATIVE HEALTH (NCCIH)

National Center for Complementary and Integrative Health

NIH...Turning Discovery Into Health

Search NCCIH

Información en español

Health Info | Research | Grants & Funding | Training | News & Events | About NCCIH

Health

All Health Topics from A-Z
Research-based info from acupuncture to zinc.

Complementary, Alternative, or Integrative Health
What do these terms mean?

Be Informed
Learn how to make wise health decisions.

Herbs at a Glance
Uses and side effects of herbs and botanicals.

How To Find a Practitioner
Information on seeking treatment.

Information for Health Care Providers
Evidence-based medicine, continuing education, clinical practice guidelines, and more.

Featured Health Topics

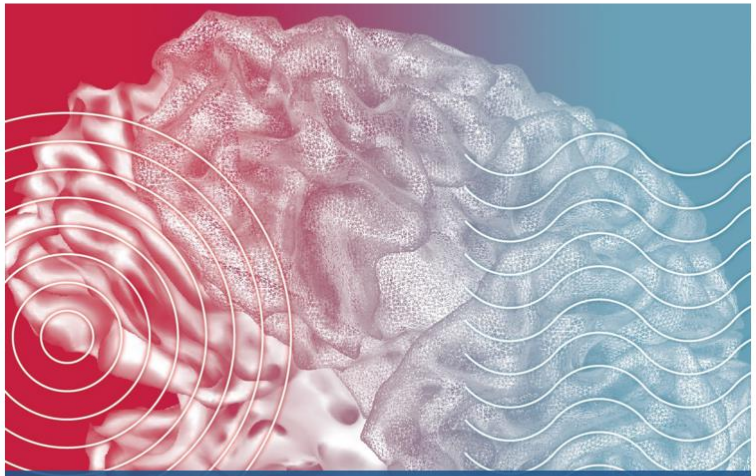
Seasonal Allergies (March 2016)

Menopausal Symptoms (February 2016)

Stress (January 2016)

News

Blog Posts

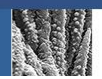


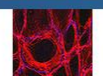
Pain Research

NCCIH sponsors and conducts pain research to learn about nonpharmacologic approaches to pain management.

Learn more about our research and find information for consumers.

Pain Research


Seasonal Allergies


Cardiovascular Health

NIH...Turning Discovery Into Health

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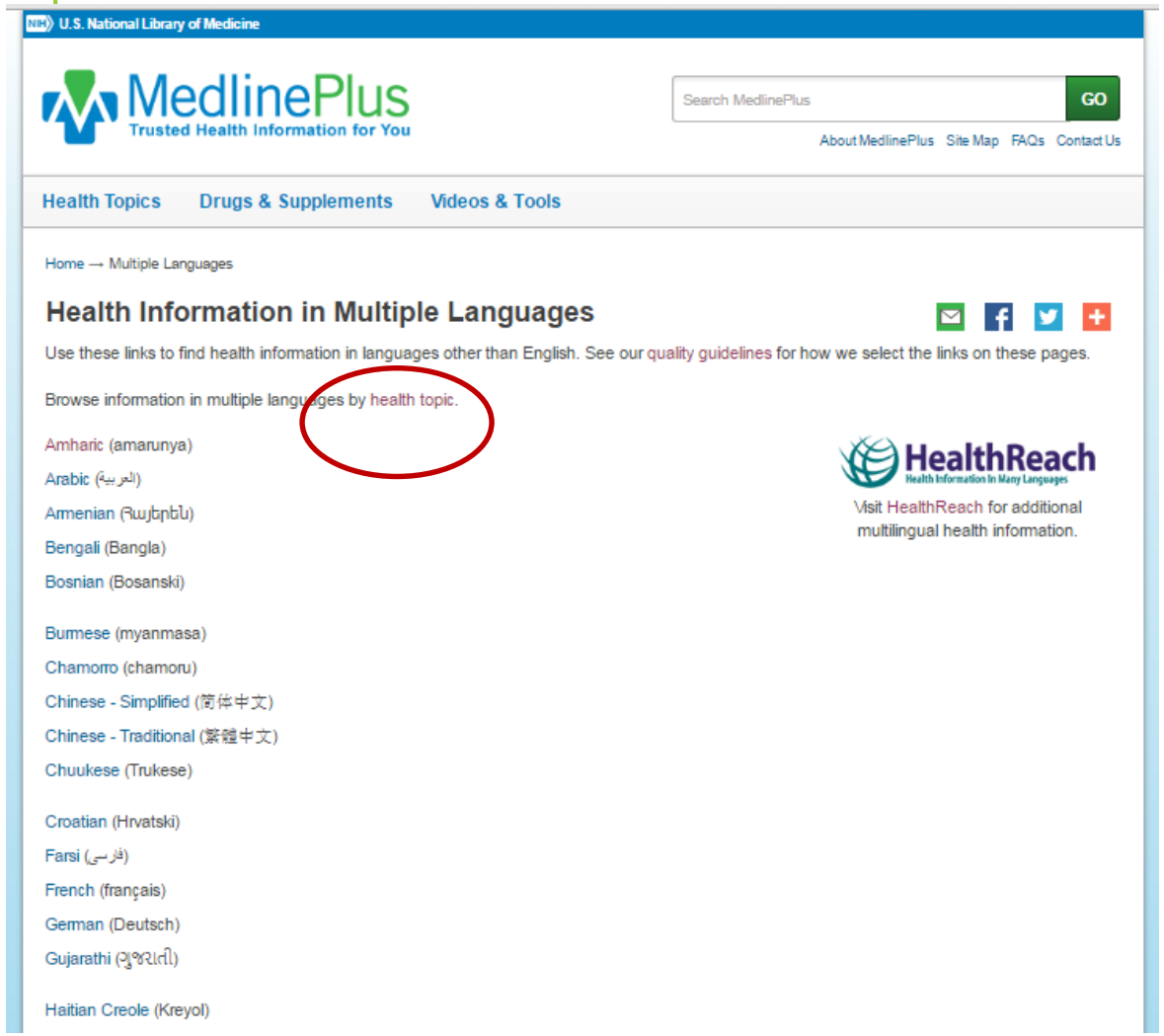
Melatonin Information

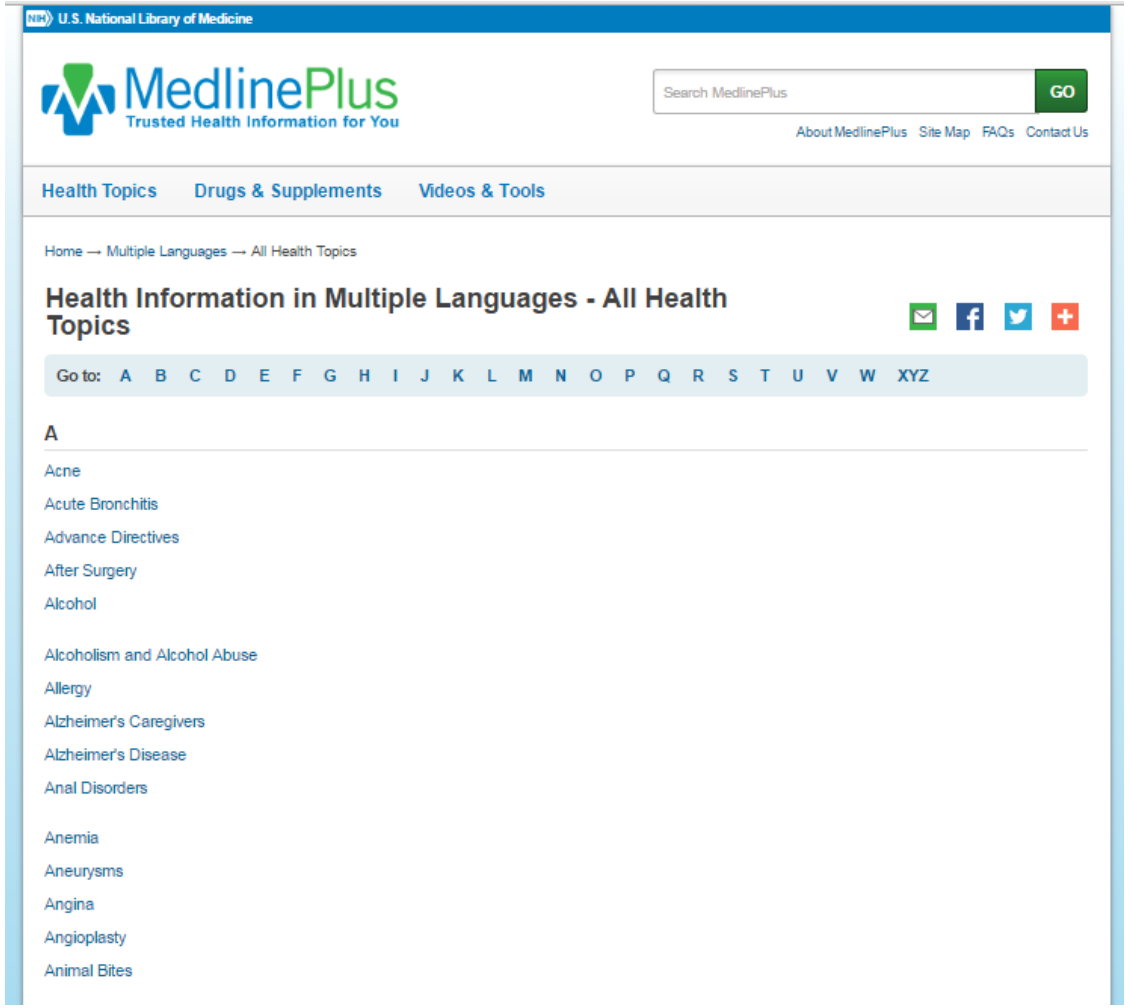
Melatonin is a natural hormone that plays a role in sleep. Melatonin dietary supplements have been studied for sleep disorders, such as jet lag, disruptions to the body's internal "clock," insomnia, and problems with sleep among people who work night shifts. It has also been studied for dementia symptoms.

- 5 Things To Know About Safety of Dietary Supplements for Children and Teens
- 7 Things To Know About Complementary Health Approaches for ASD
- 7 Things To Know About Complementary Health Approaches for ADHD
- 5 Tips: Natural Products Used for Common Aging-Related Conditions
- Melatonin: In Depth
- 5 Things To Know About Sleep Disorders and Complementary Health Approaches
- Alzheimer's Disease at a Glance
- Attention-Deficit Hyperactivity Disorder at a Glance
- Sleep Disorders: In Depth
- Sleep Disorders Information
- Autism Information

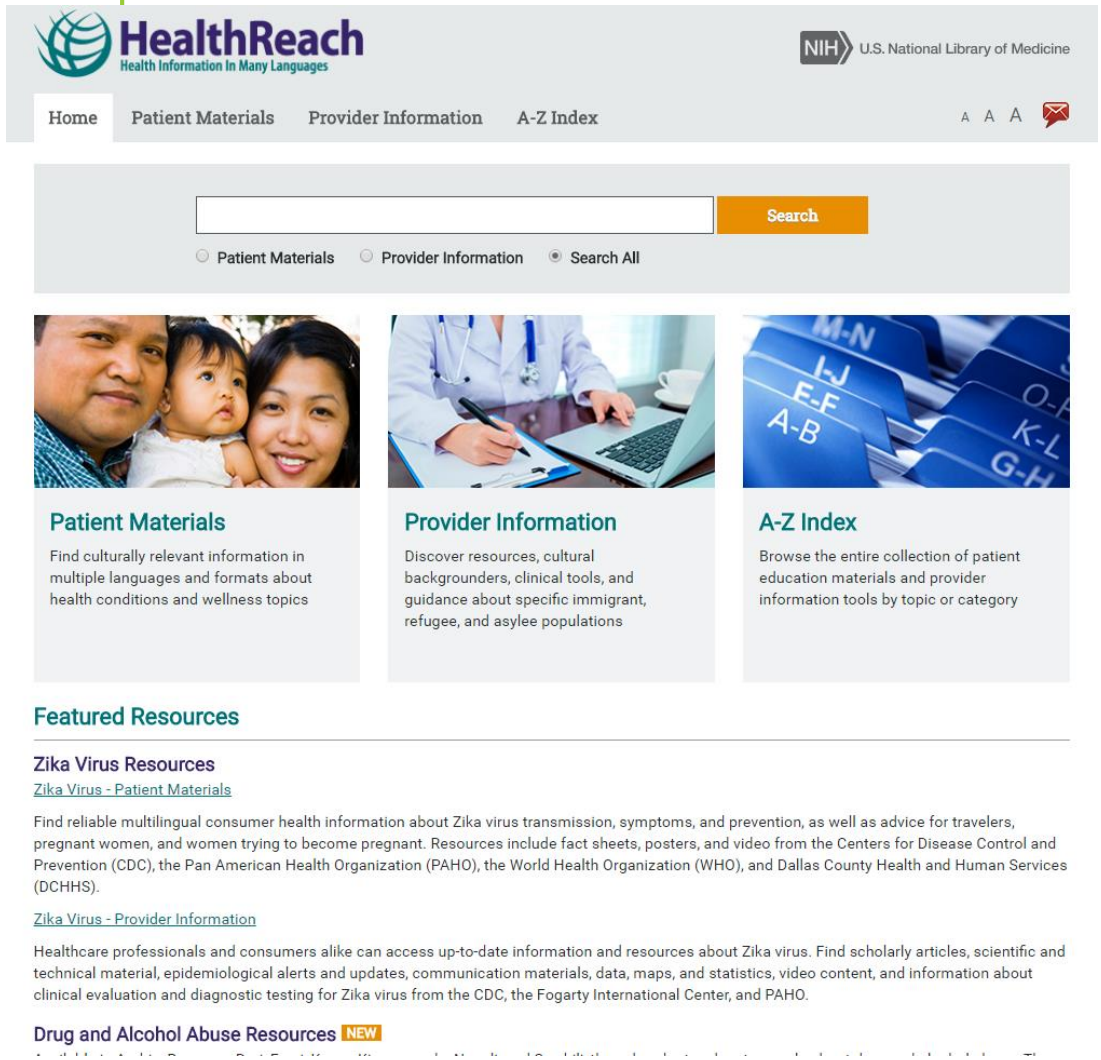
MULTIPLE LANGUAGE MATERIALS

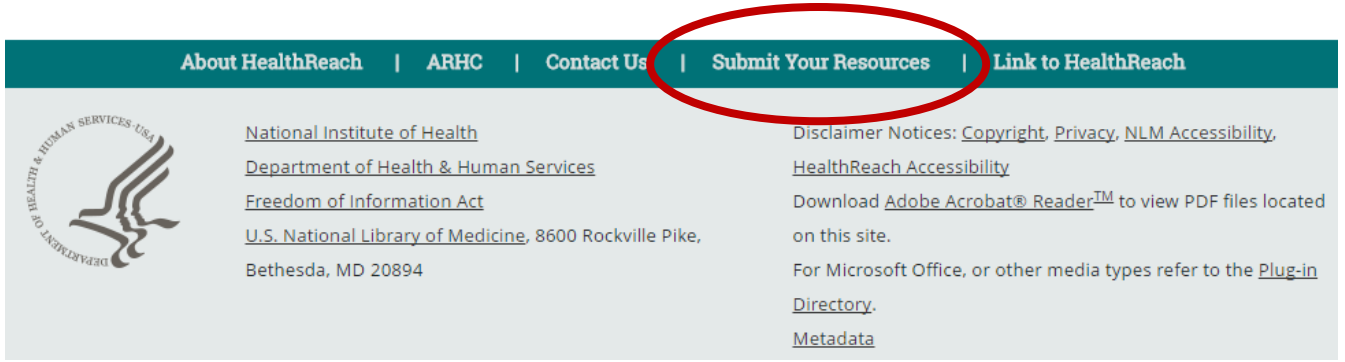
MEDLINEPLUS MULTIPLE LANGUAGES



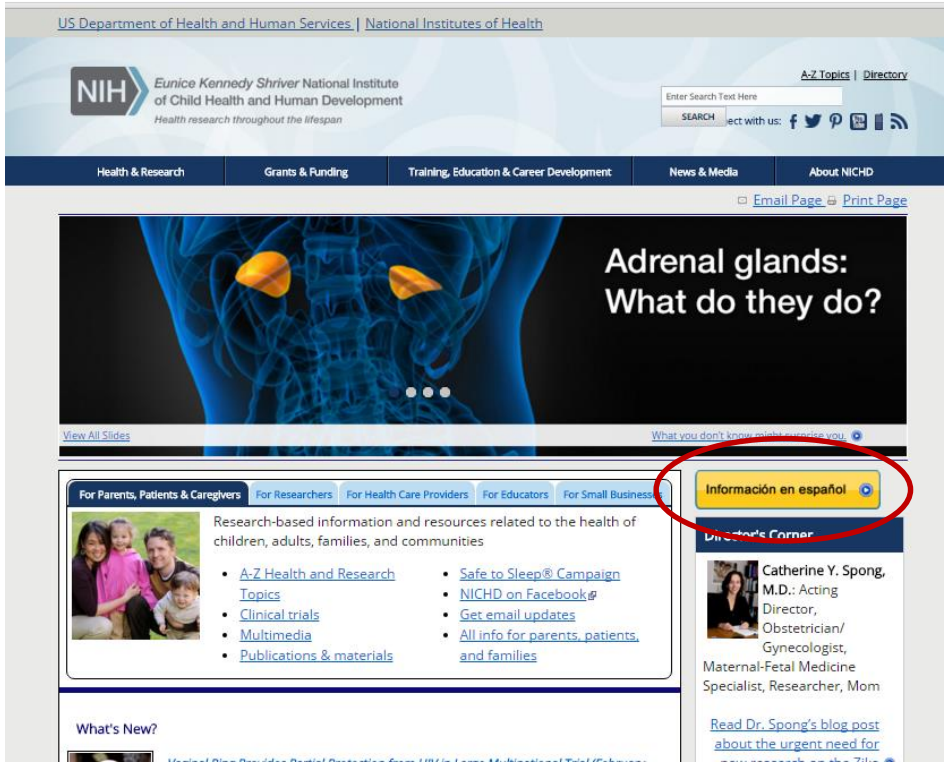


OTHER LANGUAGES





NIH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All info for parents, patients, and families
Director's Corner
Catherine Y. Spong, M.D.: Acting Director, Obstetrician/ Gynecologist, Maternal-Fetal Medicine Specialist, Researcher, Mom
Read Dr. Spong's blog post about the urgent need for
What's New?

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NIAMS Funding Plan
NIH Announces Publication of Action Plan for Lupus Research
This report was a collaborative effort, led by NIAMS on behalf of the NIH. It represents a synthesis of internal and external input on promising future research directions to improve the lives of people with lupus.
Find out more about the Action Plan.
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NIAMS Funding Opportunities
Electronic Submission of Grants
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Ongoing Research in Our Labs
Training in Our Labs
Studies Seeking Patients
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Clinical Trials at NIAMS
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more news and events
Rapid-response Immune Cells Are Fully Prepared Before Invasion Strikes
Same Immune Regulatory Protein Found to Play Instrumental Role in Two Hereditary Autoinflammatory Diseases
Bone Loss Triggered by Hormonal Condition Found to Involve Immune Molecule
NIAMS Update — April 21, 2016
Special Announcement — April 21, 2016, Guest Director's Letter: At NIH, Minority Health Is Everyone's Concern, Every Day
Study Suggests Most Women With Mild to Moderate Lupus Can Expect to Have Healthy Pregnancies
Two Drugs That Treat Rheumatoid Arthritis and Blood Cancers Shown to Promote Hair Growth
Accelerating Medicines Partnership (AMP)
NIH Accelerating Medicines Partnership
NIAMS AMP RA/Lupus Page
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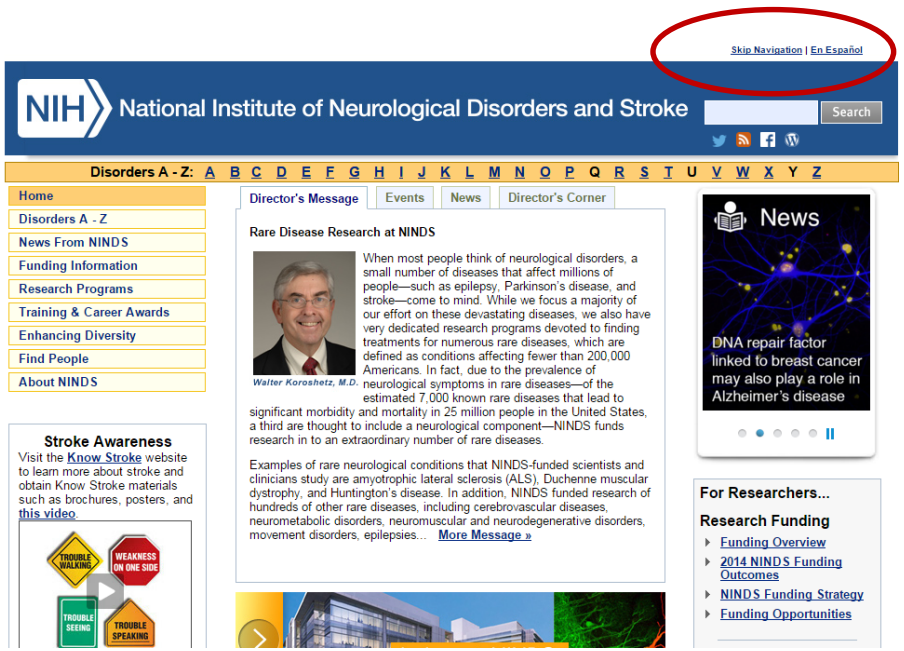
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Rare Disease Research at NINDS
Walter Koroshetz, M.D.
When most people think of neurological disorders, a small number of diseases that affect millions of people—such as epilepsy, Parkinson's disease, and stroke—come to mind. While we focus a majority of our effort on these devastating diseases, we also have very dedicated research programs devoted to finding treatments for numerous rare diseases, which are defined as conditions affecting fewer than 200,000 Americans. In fact, due to the prevalence of neurological symptoms in rare diseases—of the estimated 7,000 known rare diseases that lead to significant morbidity and mortality in 25 million people in the United States, a third are thought to include a neurological component—NINDS funds research in to an extraordinary number of rare diseases.
Examples of rare neurological conditions that NINDS-funded scientists and clinicians study are amyotrophic lateral sclerosis (ALS), Duchenne muscular dystrophy, and Huntington's disease. In addition, NINDS funded research of hundreds of other rare diseases, including cerebrovascular diseases, neurometabolic disorders, neuromuscular and neurodegenerative disorders, movement disorders, epilepsies... More Message »
Stroke Awareness
Visit the Know Stroke website to learn more about stroke and obtain Know Stroke materials such as brochures, posters, and this video.
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WEAKNESS ON ONE SIDE
TROUBLE SEEING
TROUBLE SPEAKING
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DNA repair factor linked to breast cancer may also play a role in Alzheimer's disease
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Research Funding
Funding Overview
2014 NINDS Funding Outcomes
NINDS Funding Strategy
Funding Opportunities

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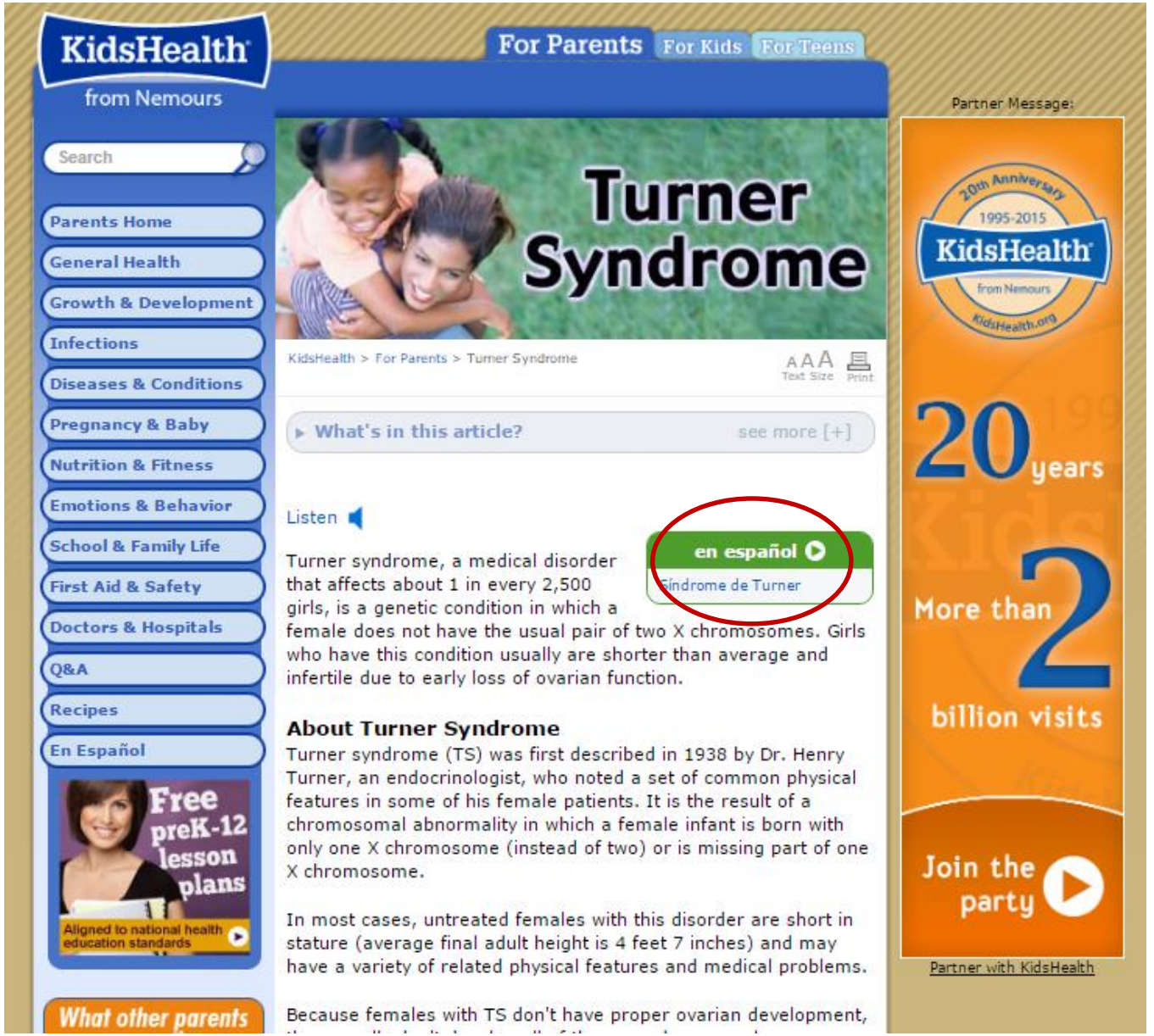

OTHER MULTI-LINGUAL LINKS

EthnoMED
Integrating cultural information into clinical practice

S*P*I*R*A*L
SELECTED PATIENT INFORMATION RESOURCES IN ASIAN LANGUAGES

Health Information Translations
Quality health education resources for diverse populations

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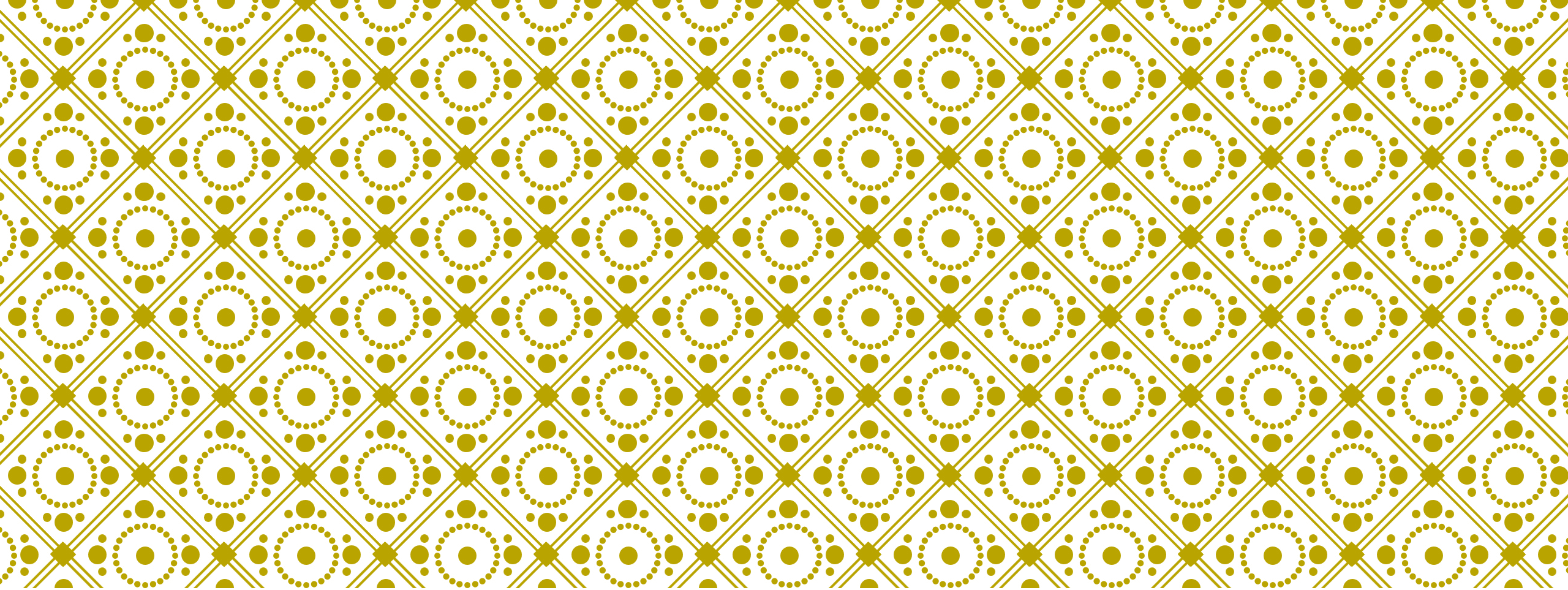


CONCERNS AND ISSUES

to consider

HEALTH NEEDS

- Comorbidity or dual diagnosis
- Dental Health
- Mental Health
- Nutrition/diet
- Locating an experienced physician
- Insurance
- Medical Home

HEALTH NEEDS- MEDLINEPLUS

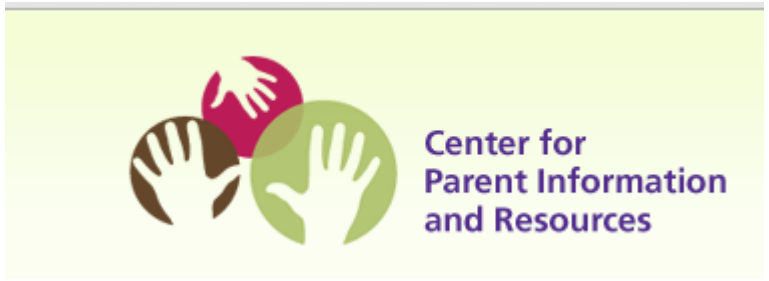
Related Issues

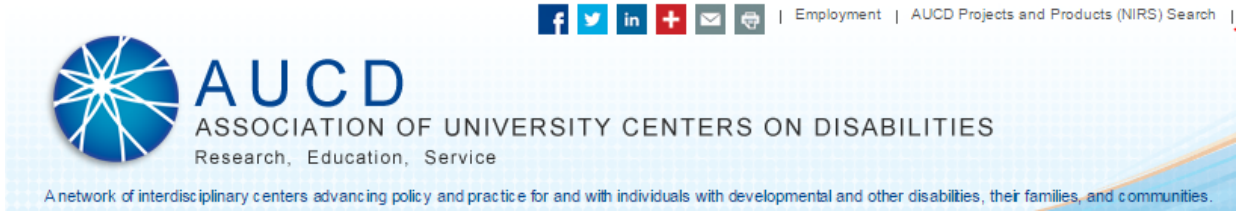
- Alzheimer's Disease in People with Down Syndrome NIH (National Institute on Aging)
- Anesthesia & Down Syndrome (National Down Syndrome Society)
- Dental Issues & Down Syndrome (National Down Syndrome Society)
- Down Syndrome Myths and Truths (National Down Syndrome Society)
  Available in Spanish
- Down Syndrome: Education (National Down Syndrome Society)
- Down Syndrome: Eye Problems (American Association for Pediatric Ophthalmology and Strabismus)
- Dual Diagnosis of Down Syndrome & Autism (National Down Syndrome Society)
- Ear, Nose & Throat Issues & Down Syndrome (National Down Syndrome Society)
- Heart and Down Syndrome (National Down Syndrome Society)
- Mental Health Issues & Down Syndrome (National Down Syndrome Society)
- Sexuality and Down Syndrome (National Down Syndrome Society)
  Available in Spanish
- Speech & Language Therapy for Children and Adolescents with Down Syndrome
  (National Down Syndrome Society)
- What Causes Down Syndrome? NIH (National Institute of Child Health and Human Development)
  Available in Spanish
- What Conditions or Disorders are Commonly Associated with Down Syndrome?
  NIH (National Institute of Child Health and Human Development)
  Available in Spanish

Genetics

- Genetics Home Reference: Down syndrome NIH (National Library of Medicine)
- Learning about Down Syndrome NIH (National Human Genome Research Institute)

RESOURCES BEYOND NLM/NIH





DENTAL HEALTH- INSUREKIDSNOW.GOV

Dental Care for Children with Special Needs

If your child has a developmental disability, a behavioral issue or a physical limitation, it's important for you to find a dentist who can give dental care while accommodating your child's unique situation. Children with special needs — like mild anxiety disorders, Down syndrome and cerebral palsy — may need extra time or support when seeing a dentist.

Supports for Special Needs at the Dentist

Finding the right dentist for your child requires balancing your child's needs with the dentist's experience. Call or visit the dentist's office to find out if the dentist is familiar with your child's condition and how it could affect his or her oral health. Describe the special supports your child may need and ask whether the dentist can provide them. When looking for a dentist, think about these special supports and dentist qualifications:

- **PRE-APPOINTMENTS:** Does the dentist offer pre-appointments? A pre-appointment would give your child a chance to meet the dentist and see the exam room and equipment. This could help your child feel more comfortable and be more cooperative during the actual dental appointment.
- **ACCESSIBILITY:** Are the areas inside and outside the dentist's office accessible for your child? If your child uses a wheelchair, you'll want to find a dentist's office where the wheelchair will fit through the front door and in the examination room.
- **EXPERIENCE:** Dentists and their staff who have already cared for children with special needs may have developed strategies that could help support your child. They may also be able to give you advice on oral health home care, like tips for brushing teeth.
- **SPECIALIZED CLINICAL TRAINING:** Some general dentists and most pediatric dentists get special training to treat children with special needs. Before scheduling an appointment, find out whether the dentist has had such training.
- **SEDATION:** Some children may need general anesthesia, while others may need some mild sedation, which can be given by mouth or from an IV drip. Speak with the dentist about your child's options,and find out what he or she recommends for your child.

Steps to Finding the Right Dentist

These resources can help you find a dentist who can meet your child's special needs.

- Use the Insure Kids Now Dental Locator on **www.InsureKidsNow.gov** to find nearby dentists that accept Medicaid coverage. Enter your child's state, Medicaid plan name, and ZIP code or address. Hit "Search." Under the "More Information" column, look for the dentists that "Can Accommodate Special Needs." Before you make an appointment, call or visit the dentist's office to talk about your child's special needs.
- Family Voices is a network of experienced family members of children with special needs. Connect with Family Voices in your state at **www.FamilyVoices.org/states** to find information on a variety of topics, as well as referrals and support from other families.

Health Insurance Marketplace

InsureKidsNow.gov

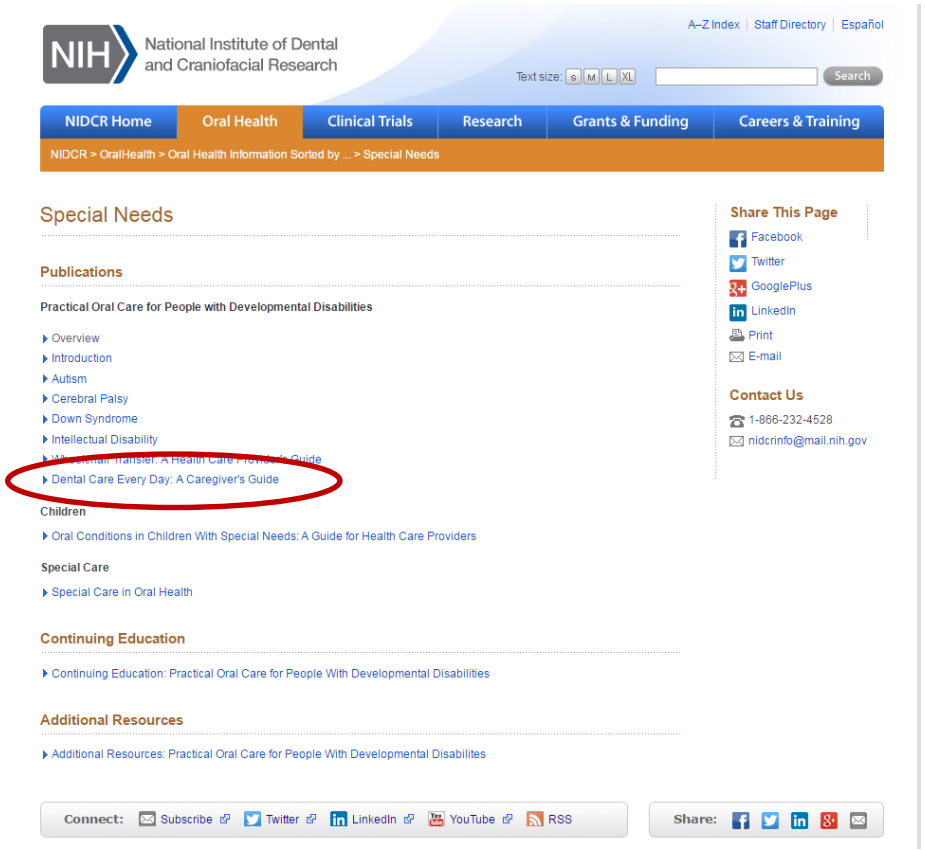
Go to **InsureKidsNow.gov** or call **1-877-KIDS-NOW** to learn more about **Medicaid** and the **Children's Health Insurance Program** and how to enroll your eligible child.

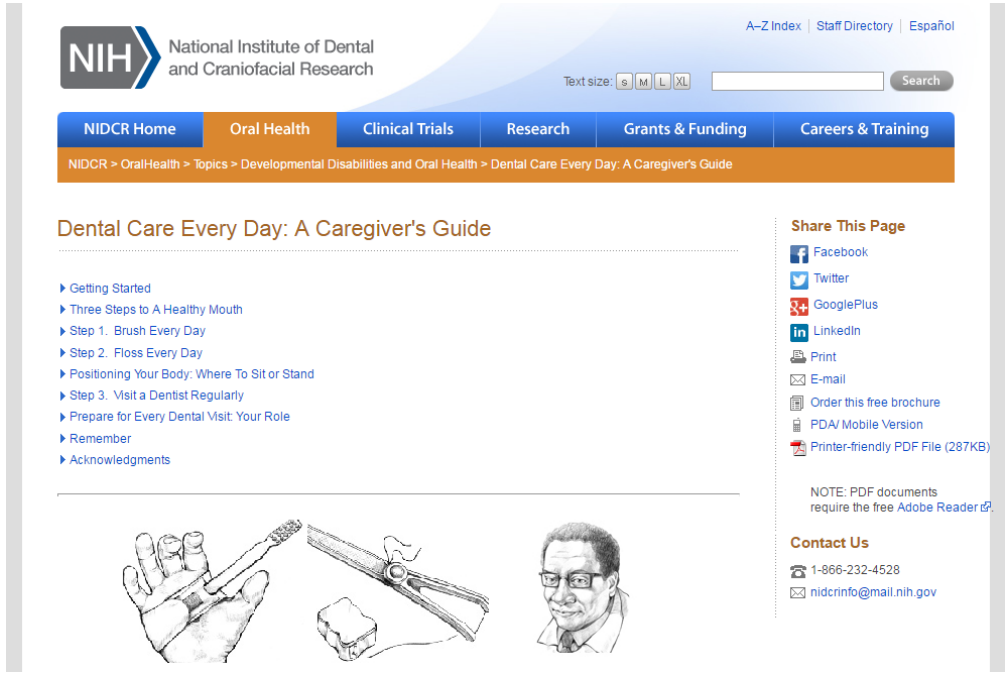
These programs cover the dental benefits children need.

Visit **HealthCare.gov** to learn more about affordable health coverage for your family.

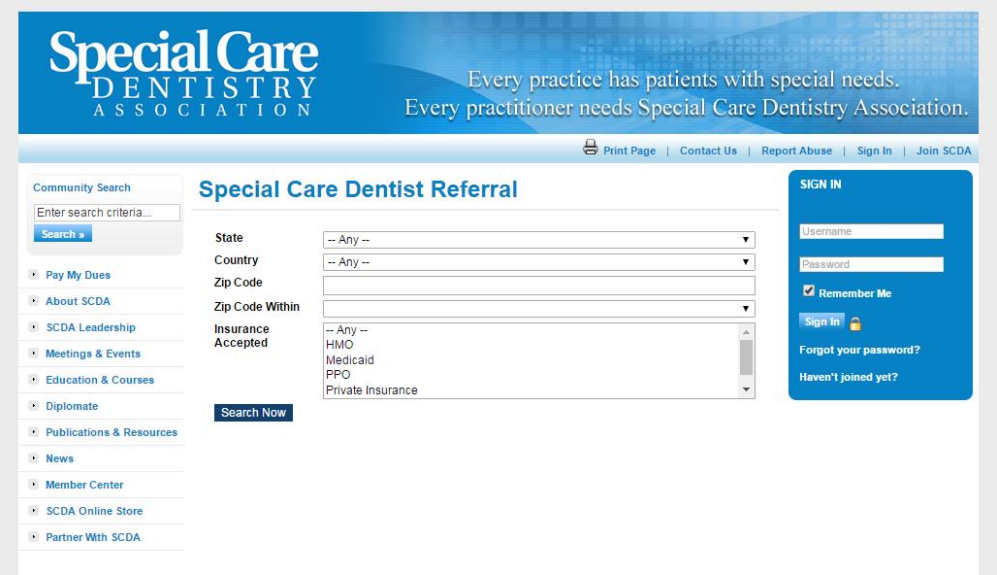
CMS Product No.11895
January 2015

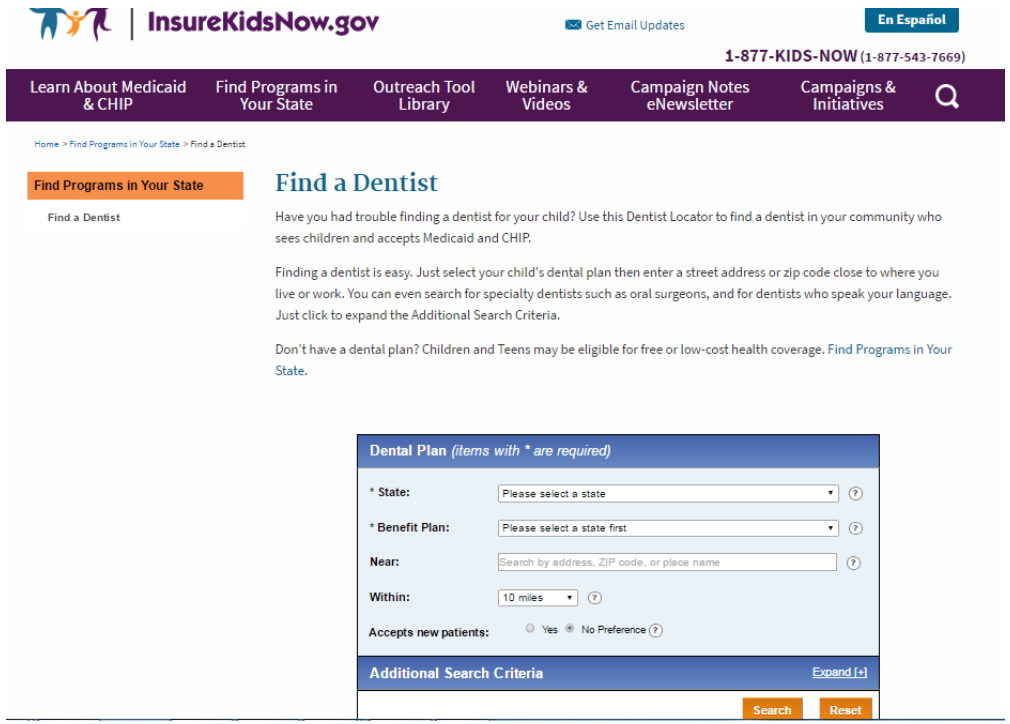
DENTAL HEALTH- NIH NIDCR



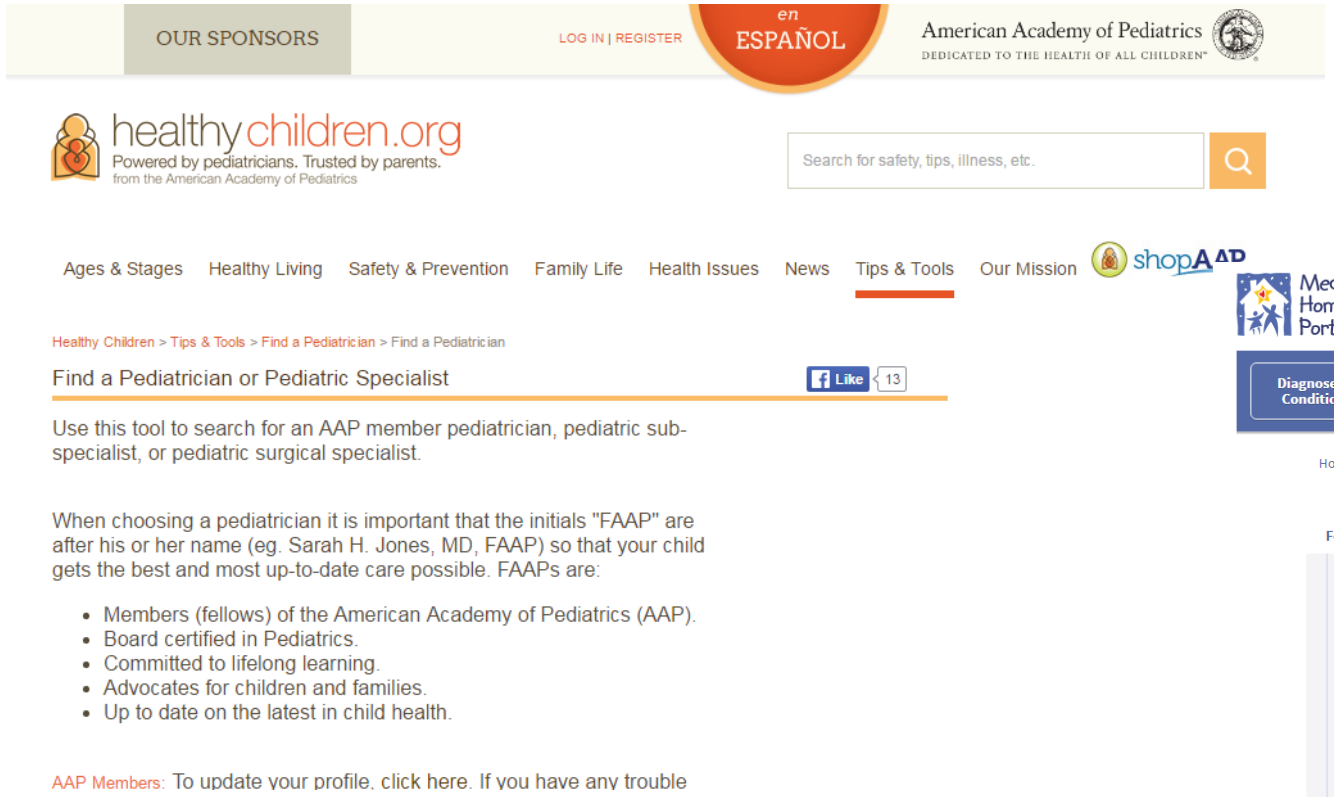


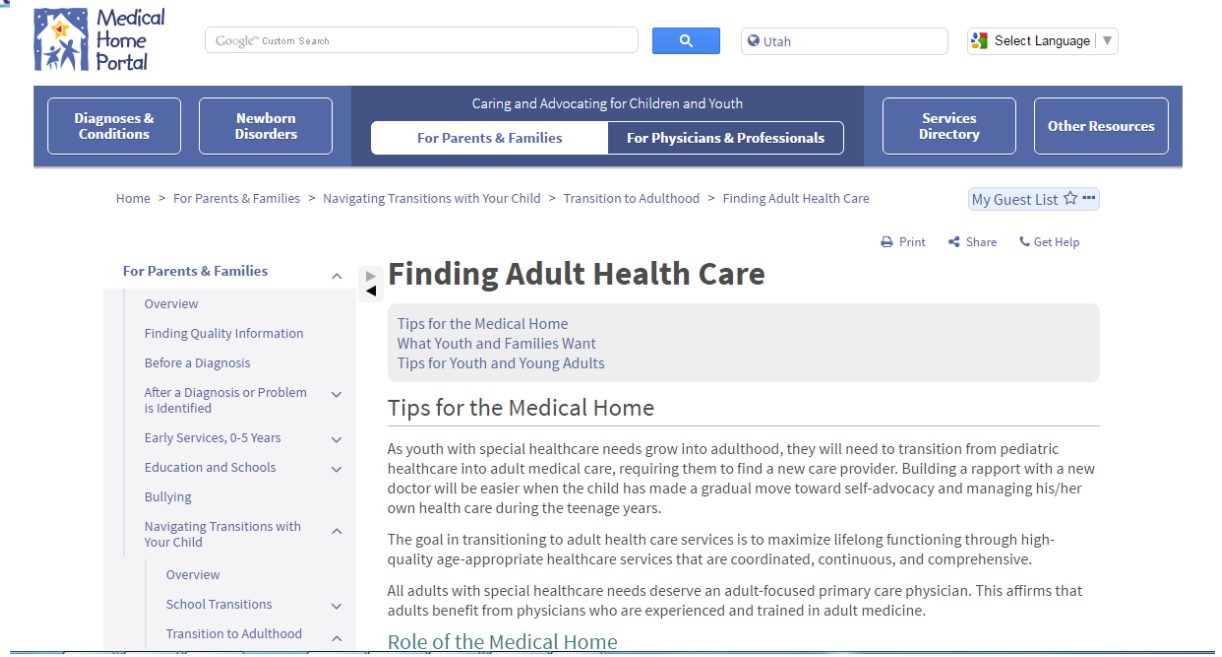
FINDING A DENTIST



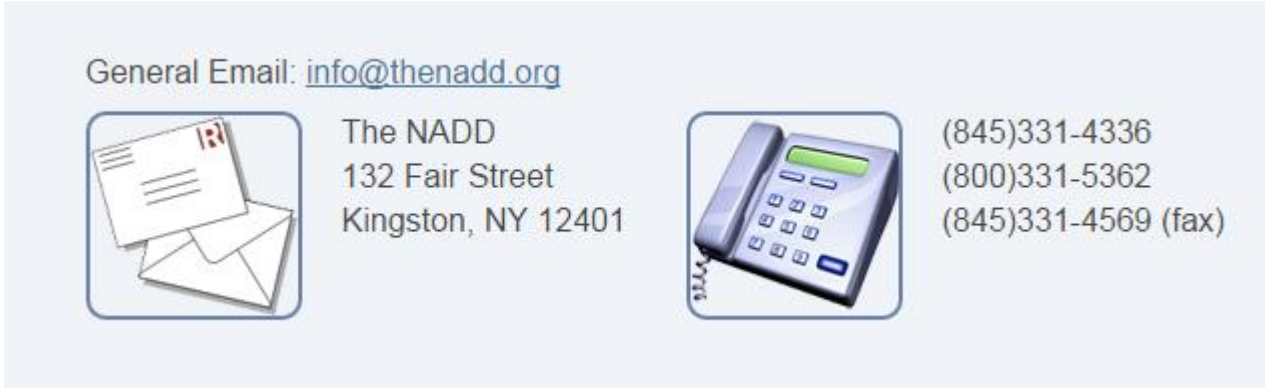


LOCATING A PHYSICIAN





MENTAL HEALTH



MENTAL HEALTH- FAMILY VOICES

FAMILY VOICES®
...keeping families at the center of children's health care

SITE MAP

SEARCH THE SITE... | GO

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♥ MEDIA CENTER

PRINT SHARE

May 16, 2015

New Resources on Mental Health

Explanation of Mental Disorders -- Plain-Language Guide to the DSM-5

As explained in this article from *Kaiser Health News*, the American Psychiatric Association (APA) has released a plain-English guide to the new the Diagnostic and Statistical Manual of Mental Disorders. The book, Understanding Mental Disorders: Your Guide To DSM-5, includes in-depth explanations of risk factors, symptoms and symptom management, treatment options, and success stories, designed to help those with mental health problems, as well as their families, friends, and co-workers. As noted by the APA, the book is intended to help readers recognize symptoms, know when to seek help, and get the right care, thereby helping them to better advocate for themselves. Featured disorders include depression, schizophrenia, ADHD, autism spectrum disorder, posttraumatic stress disorder, and bipolar disorder.

Children's Mental Health Guide for Families from SPAN of NJ

This guide 6-page guide, available in English and Spanish, include the following topics:

- What parents and professionals need to know about mental health
- When to get help

MORE IN THIS SECTION »

PRESS RELEASES

AFFORDABLE CARE ACT (ACA)

TAKE ACTION

SHARE YOUR STORY

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ADVOCATE

JOIN US

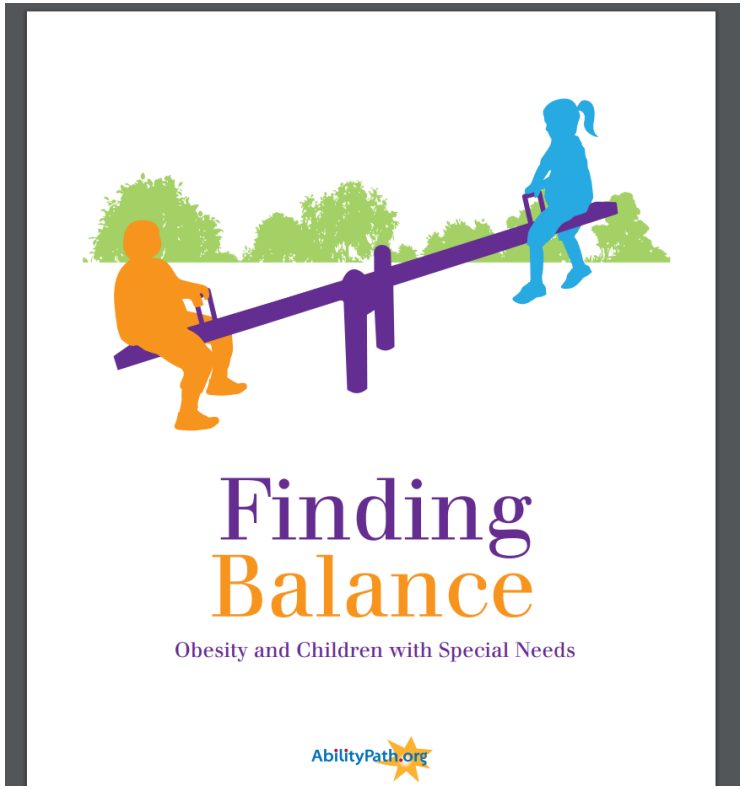
CONTACT US

DONATE NOW

CHILDREN'S MENTAL HEALTH SERVICES:

A FAMILY GUIDE

HEALTHY LIVING



HealthMatters™ Program

Real People, Practical Solutions, Real Changes

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Resources | News Archive | Why Health Matters

1. Getting the Memo

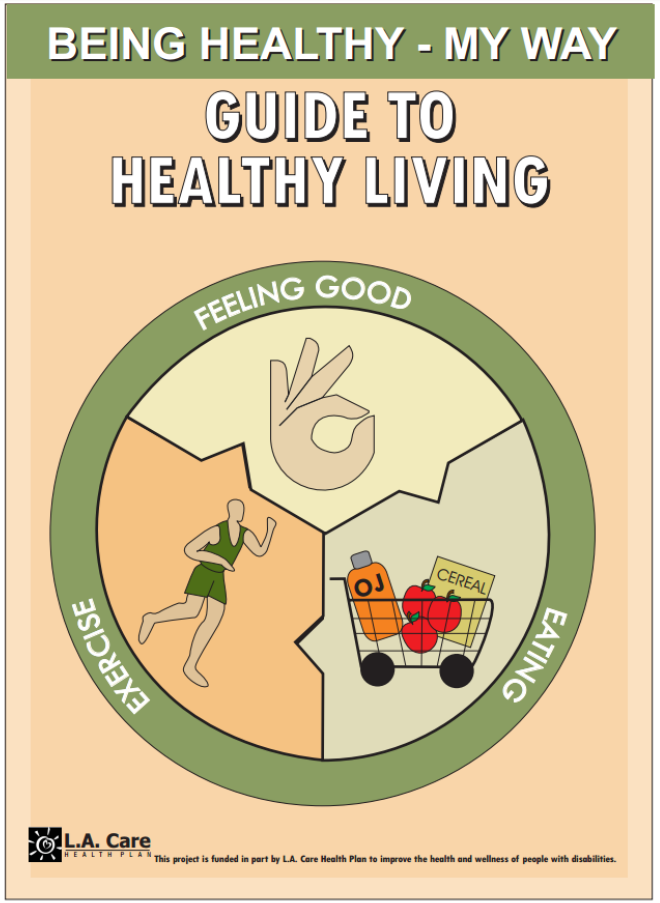
Interactive Atlas - View county-level maps of heart disease and stroke, along with maps of social environmental conditions and health services for the entire United States or for a chosen state or territory.
The Power of Prevention - A publication covering chronic diseases, what causes them and at what cost.
Heart Disease Fact Sheet - Heart disease facts, risk factors, and public health campaigns.
National Core Indicators - NCI™ is a voluntary effort by public developmental disabilities agencies to measure and track their own performance.
Nutrition for Everyone - resources to help you start healthier eating habits.
Nutrition Basics - basic concepts related to nutrition to keep in mind.

2. Am I ready? Is my Organization ready?

Body Mass Index Calculator
Fruit and Vegetable Serving Calculator
Portion Distortion - Compare portion sizes from 20 years ago to present. Fun, interactive activities.
What Counts as a Cup? - examples of foods and serving sizes.
VIDEO Beyond Disability - Empowered Fe Fes (slang for female), a group of young women with disabilities, hit the streets of Chicago on a quest to discover the difference between how they see themselves and how others see them.

3. Making Lifestyle Changes

VIDEO **HealthMatters Program!**
Thera-Band Academy - has over 900 exercises using Thera-Band products that you can search for and create



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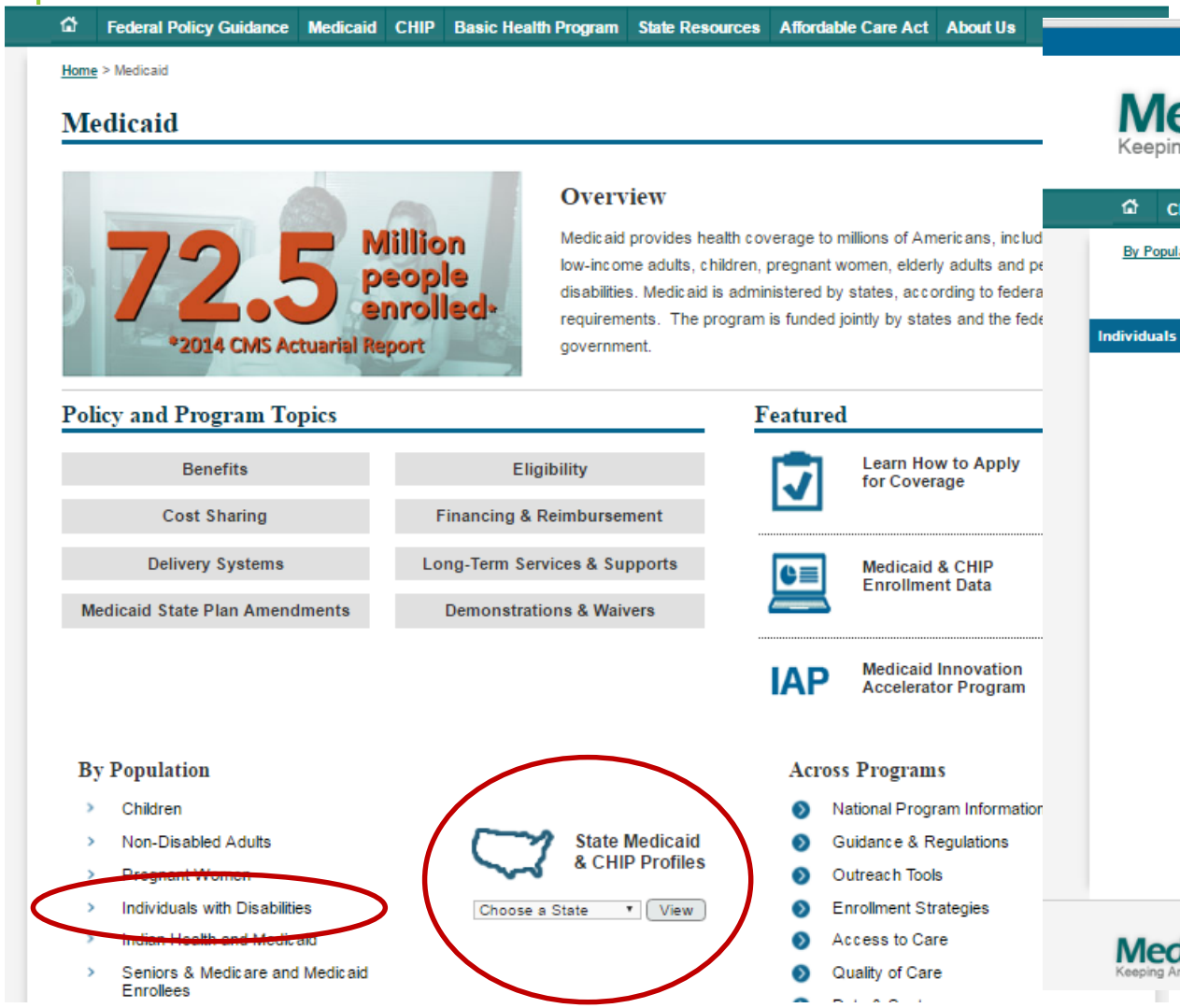
Federal Policy Guidance
Medicaid
CHIP
Basic Health Program
State Resources
Affordable Care Act
About Us
Home > Medicaid
Medicaid
72.5 Million people enrolled*
*2014 CMS Actuarial Report
Overview
Medicaid provides health coverage to millions of Americans, includ
low-income adults, children, pregnant women, elderly adults and pe
disabilities. Medicaid is administered by states, according to federa
requirements. The program is funded jointly by states and the fede
government.
Policy and Program Topics
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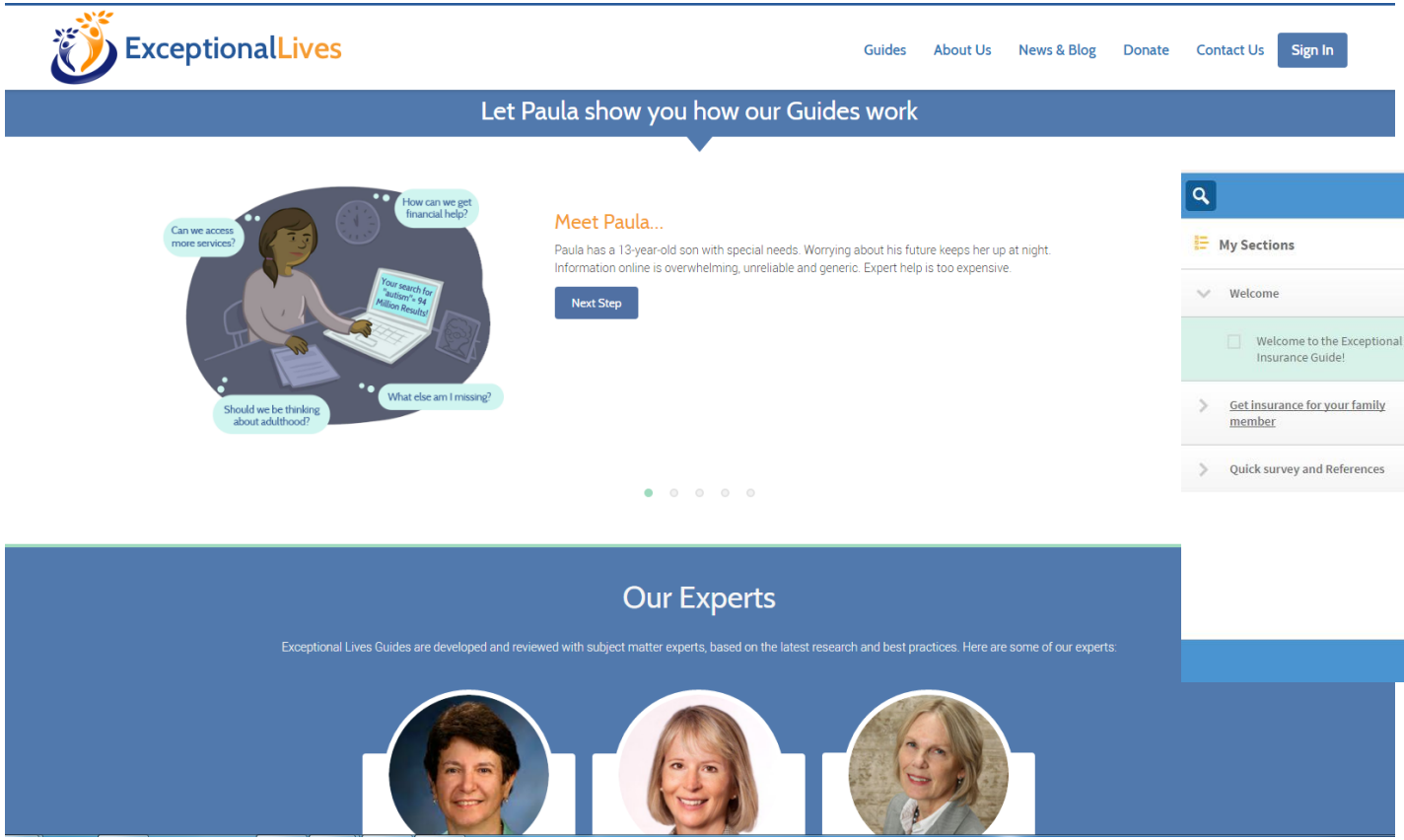
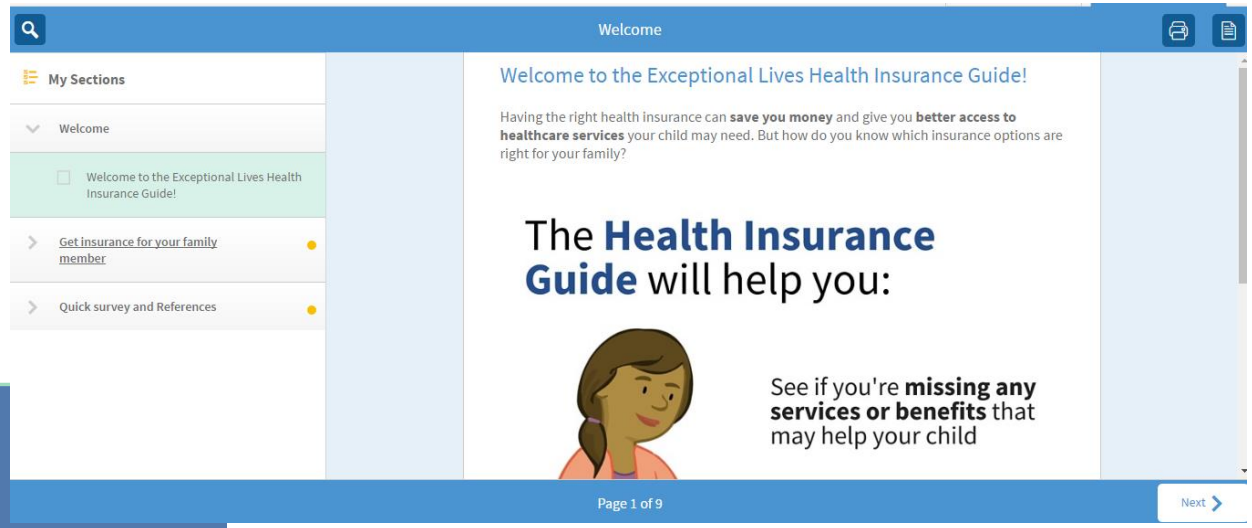
Eligibility
Cost Sharing
Financing & Reimbursement
Delivery Systems
Long-Term Services & Supports
Medicaid State Plan Amendments
Demonstrations & Waivers
Featured
Learn How to Apply for Coverage
Medicaid & CHIP Enrollment Data
IAP
Medicaid Innovation Accelerator Program
By Population
Children
Non-Disabled Adults
Pregnant Women
Individuals with Disabilities
Indian Health and Medicaid
Seniors & Medicare and Medicaid Enrollees
State Medicaid & CHIP Profiles
Choose a State
View
Across Programs
National Program Information
Guidance & Regulations
Outreach Tools
Enrollment Strategies
Access to Care
Quality of Care

Archive CMS.gov Site Map FAQs
Learn about your healthcare options
Medicaid.gov
Keeping America Healthy
Stay Connected
Website Feedback
Children
Adults
Pregnant Women
Individuals with Disabilities
Seniors & Medicare and Medicaid Enrollees
By Population > Individuals with Disabilities
Individuals with Disabilities
Individuals with Disabilities
Medicaid provides health coverage to over 8.8 million non-elderly individuals with disabilities, including those who are working or who want to work. Federal statute provides for both mandatory and optional coverage for individuals with disabilities.
Eligibility
Many individuals who qualify for Medicaid based on disability also receive cash assistance under the Supplemental Security Income (SSI) program. In almost all states, SSI eligibility automatically qualifies an individual for Medicaid coverage. However, some states use more restrictive eligibility criteria than those used by the SSI program. This means that in those states (commonly referred to as 209(b) states) receipt of SSI does not guarantee eligibility for Medicaid. Individuals not receiving SSI but seeking coverage based on disability must demonstrate that they have an impairment that prevents them from performing "substantial gainful activity" for at least one year. Once a disability determination is made, the individual must then undergo an asset test and meet specific income requirements in order to be considered for Medicaid eligibility.
Benefits
Individuals with disabilities who are eligible for Medicaid are entitled to all services that are deemed medically necessary. Many require and receive long term services and supports. These services can be provided through a variety of delivery systems.
Apply for COVERAGE
Related Resources
Medicaid Benefits
Long-Term Services & Supports
Delivery Systems
Balancing
Integrating Care
Medicaid.gov
Keeping America Healthy
A federal government managed website by the Centers for Medicare & Medicaid Services. 7500 Security Boulevard Baltimore, MD 21244

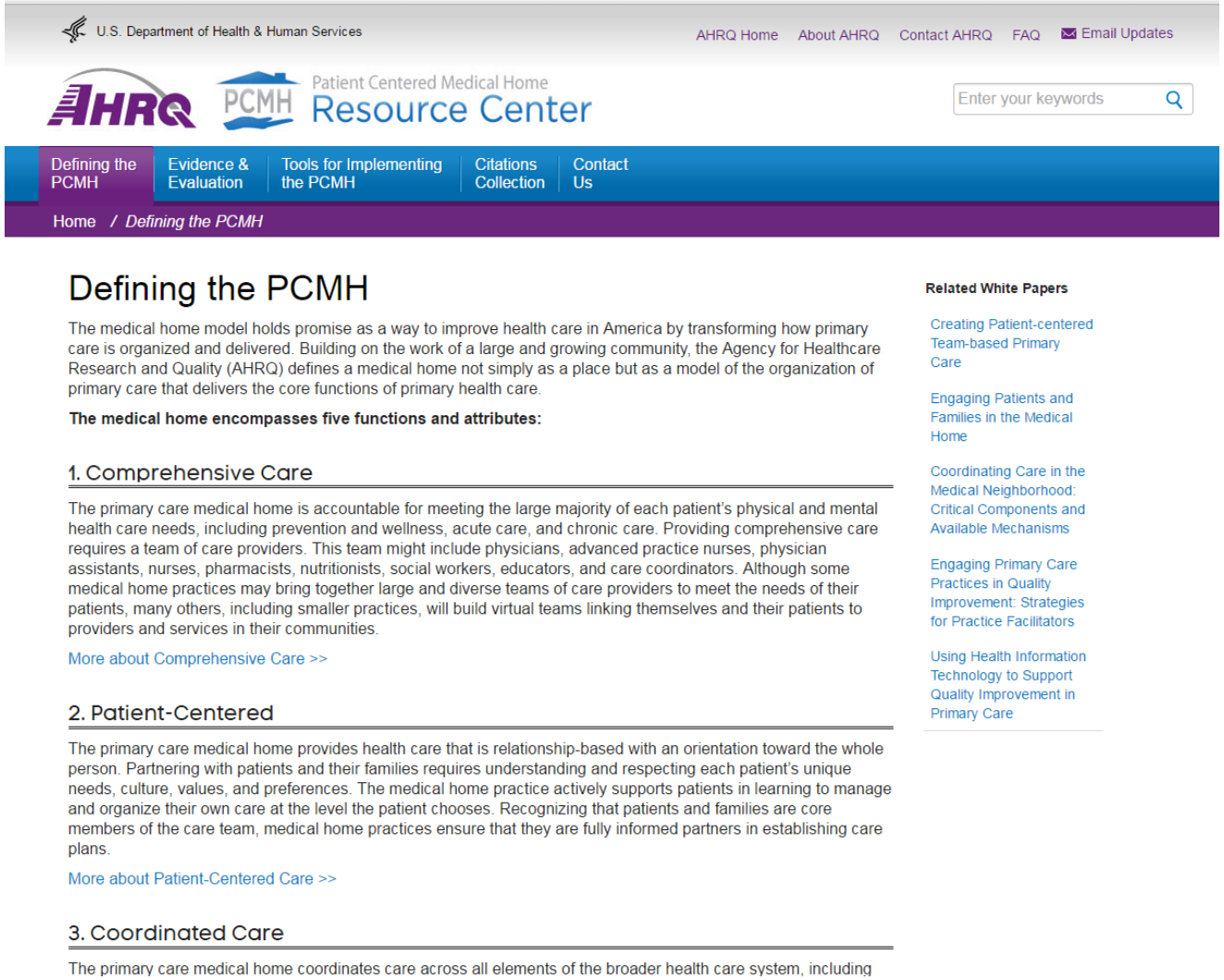
INSURANCE- HEALTHCARE.GOV

INSURANCE- EXCEPTIONAL LIVES





MEDICAL HOME- AHRQ



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AHRQ PCMH Patient Centered Medical Home Resource Center

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Defining the PCMH

The medical home model holds promise as a way to improve health care in America by transforming how primary care is organized and delivered. Building on the work of a large and growing community, the Agency for Healthcare Research and Quality (AHRQ) defines a medical home not simply as a place but as a model of the organization of primary care that delivers the core functions of primary health care.

The medical home encompasses five functions and attributes:

1. Comprehensive Care

The primary care medical home is accountable for meeting the large majority of each patient's physical and mental health care needs, including prevention and wellness, acute care, and chronic care. Providing comprehensive care requires a team of care providers. This team might include physicians, advanced practice nurses, physician assistants, nurses, pharmacists, nutritionists, social workers, educators, and care coordinators. Although some medical home practices may bring together large and diverse teams of care providers to meet the needs of their patients, many others, including smaller practices, will build virtual teams linking themselves and their patients to providers and services in their communities.

More about Comprehensive Care >>

2. Patient-Centered

The primary care medical home provides health care that is relationship-based with an orientation toward the whole person. Partnering with patients and their families requires understanding and respecting each patient's unique needs, culture, values, and preferences. The medical home practice actively supports patients in learning to manage and organize their own care at the level the patient chooses. Recognizing that patients and families are core members of the care team, medical home practices ensure that they are fully informed partners in establishing care plans.

More about Patient-Centered Care >>

3. Coordinated Care

The primary care medical home coordinates care across all elements of the broader health care system, including

Related White Papers

- Creating Patient-centered Team-based Primary Care
- Engaging Patients and Families in the Medical Home
- Coordinating Care in the Medical Neighborhood: Critical Components and Available Mechanisms
- Engaging Primary Care Practices in Quality Improvement: Strategies for Practice Facilitators
- Using Health Information Technology to Support Quality Improvement in Primary Care

MEDICAL HOME- AAP

CAREGIVERS

- Almost half are over age 50
  - 1/3 fair to poor health
- Caregiving causes heavy emotional, physical and financial toll
- Experience conflicting emotions
- 22% caregivers taking care of 2
- 8% caregivers taking care of 3 or more

Administration on Aging, National Family Caregiver Support Program http://www.aoa.acl.gov/AoA_Programs/HCLTC/Caregiver/

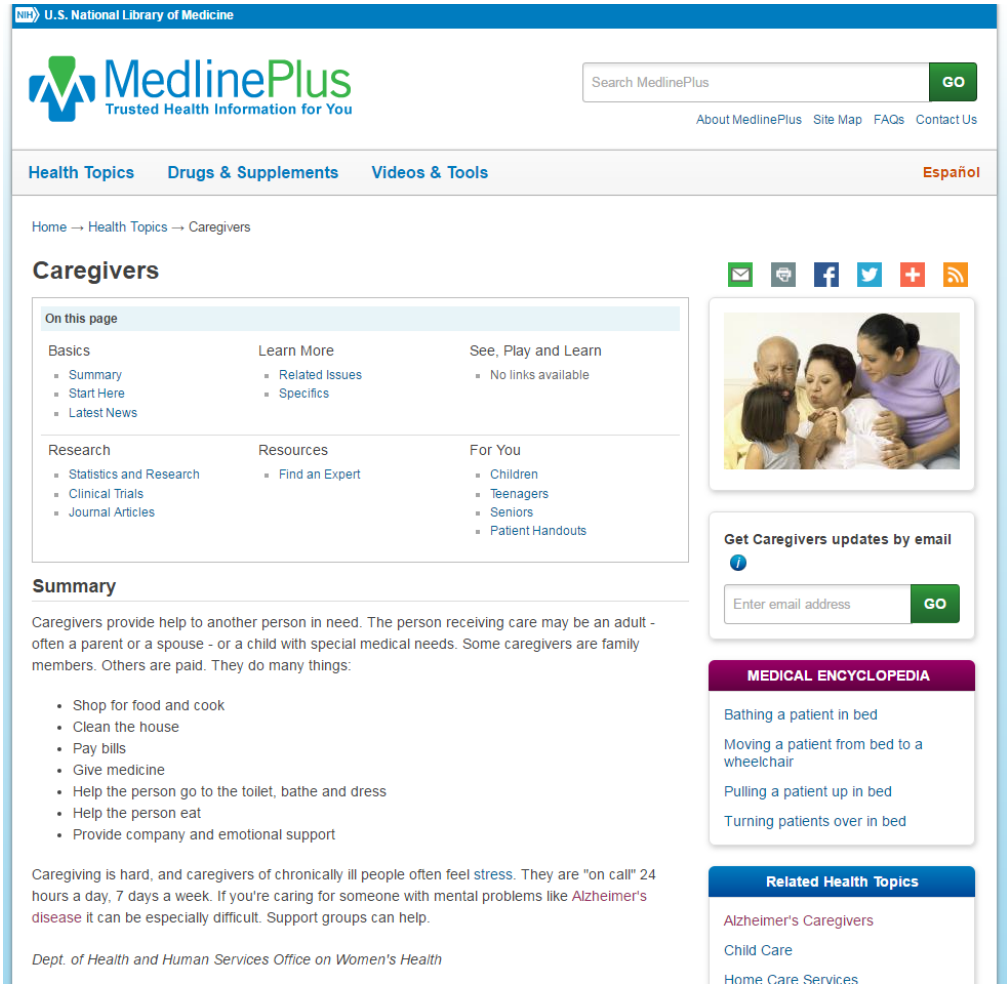
CAREGIVER- BENEFITS

- Find meaning or sense of purpose
- Coping mechanism
- Personal satisfaction
- Increased confidence
- Increased family bond
- Increased health

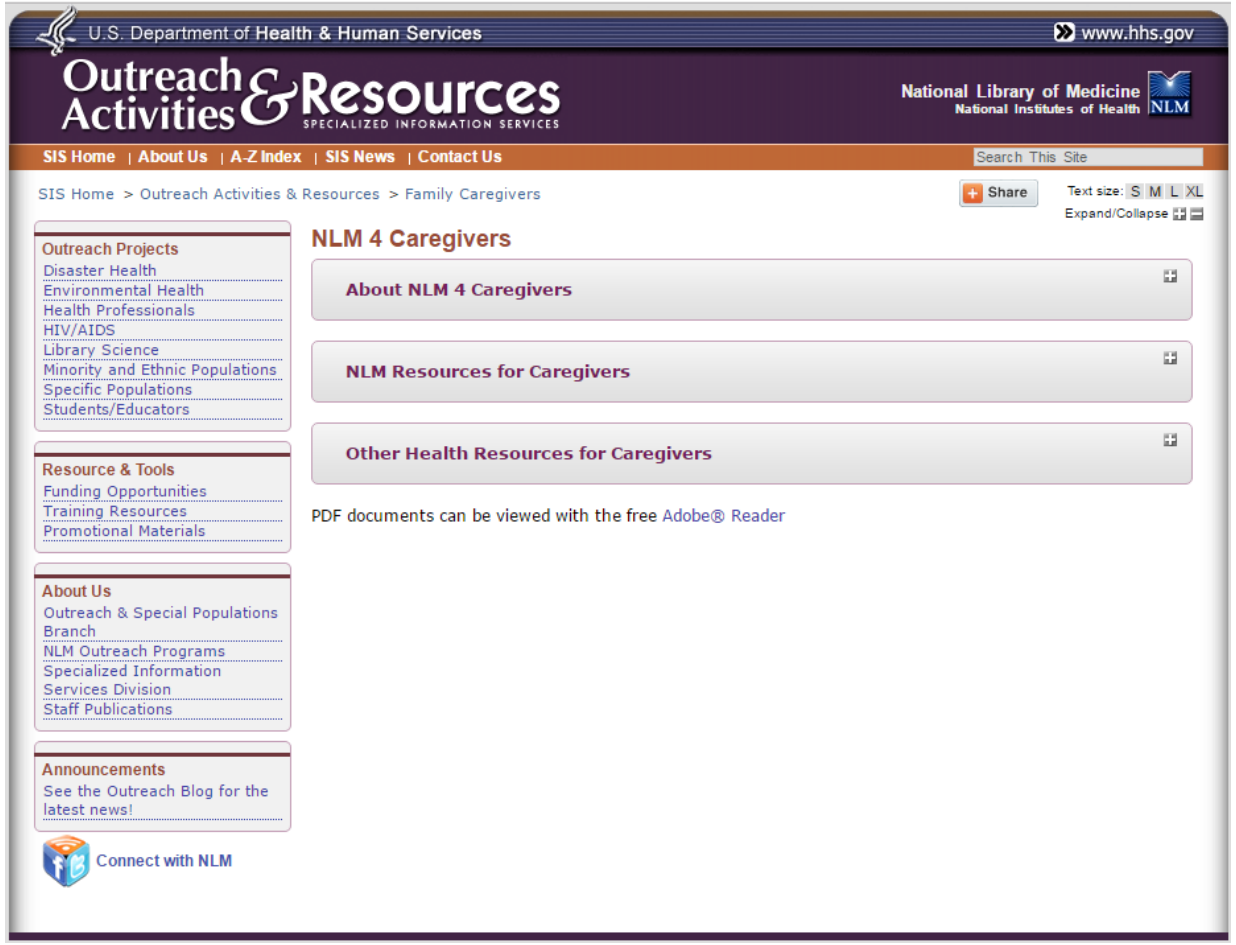
CAREGIVER- CHALLENGES

- Financial burdens
- Physical challenges
- Emotional needs
- Employment factors
- Isolation

CAREGIVERS- MEDLINEPLUS



NLM 4 CAREGIVERS



CAREGIVER SUPPORT

Caring for the Caregiver
A Message of Hope and Help for Caregivers

CDC Centers for Disease Control and Prevention
CDC 24/7: Saving Lives, Protecting People™

The Arc.
For people with intellectual and developmental disabilities

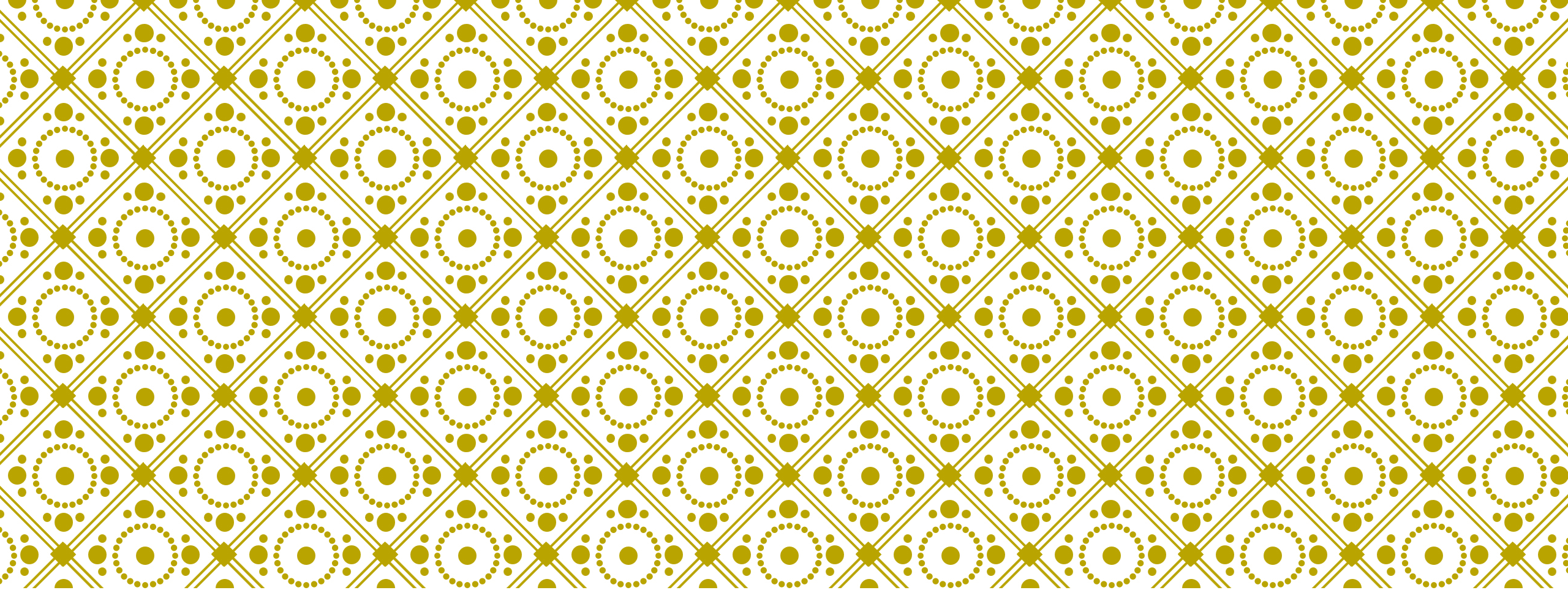
FAMILY VOICES®
...keeping families at the center of children's health care

FCA FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving

ARCH National Respite Network
And Resource Center

CAREGIVER ACTION NETWORK CAN

SiblingSupportProject
Our brothers, our sisters, ourselves...
Log in



INTERACTING

Language and Etiquette

INTERACTING- CDC

Communicating With and About People with Disabilities

About 50 million Americans report having a disability. Most Americans will experience a disability some time during the course of their lives. Disabilities can affect people in different ways, even when one person has the same type of disability as another person. Some disabilities may be hidden or not easy to see.

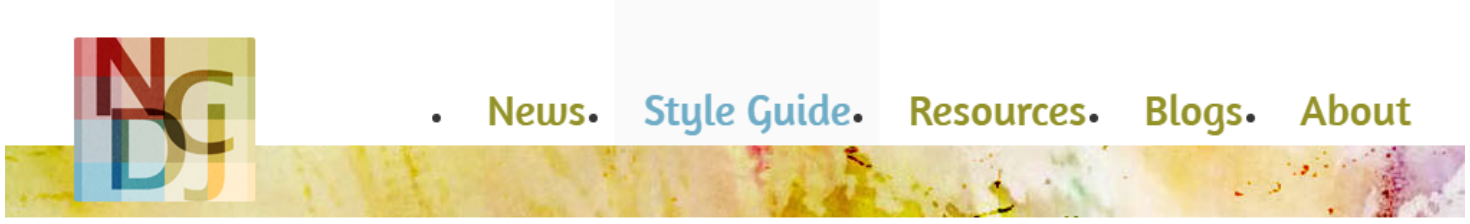
People First Language

People first language is used to speak appropriately and respectfully about an individual with a disability. People first language emphasizes the person first not the disability. For example, when referring to a person with a disability, refer to the person first by using phrases such as: "a person who …", "a person with …" or, "person who has…"

Here are suggestions on how to communicate with and about people with disabilities.

People First Language	Language to Avoid
Person with a disability	The disabled, handicapped
Person without a disability	Normal person, healthy person
Person with an intellectual, cognitive, developmental disability	Retarded, slow, simple, moronic, defective or retarded, afflicted, special person
Person with an emotional or behavioral disability, person with a mental health or a psychiatric disability	Insane, crazy, psycho, maniac, nuts
Person who is hard of hearing	Hearing impaired, suffers a hearing loss
Person who is deaf	Deaf and dumb, mute
Person who is blind/visually impaired	The blind
Person who has a communication disorder, is unable to speak, or uses a device to speak	Mute, dumb

INTERACTING- NATIONAL CENTER ON DISABILITY AND JOURNALISM



Disability Language Style Guide

• A • B • C • D • E • F • H • I • L • M • O • Q • R • T • V

The style guide is intended for journalists, communication professionals and members of the general public who are seeking the appropriate and accurate language to use when writing or talking about people living with disabilities. The guide covers general terms and words on physical disabilities, hearing and visual impairments, mental and cognitive disabilities and seizure disorders. Entries are listed in alphabetical order. Click on the index above to jump to entries that begin with that letter.

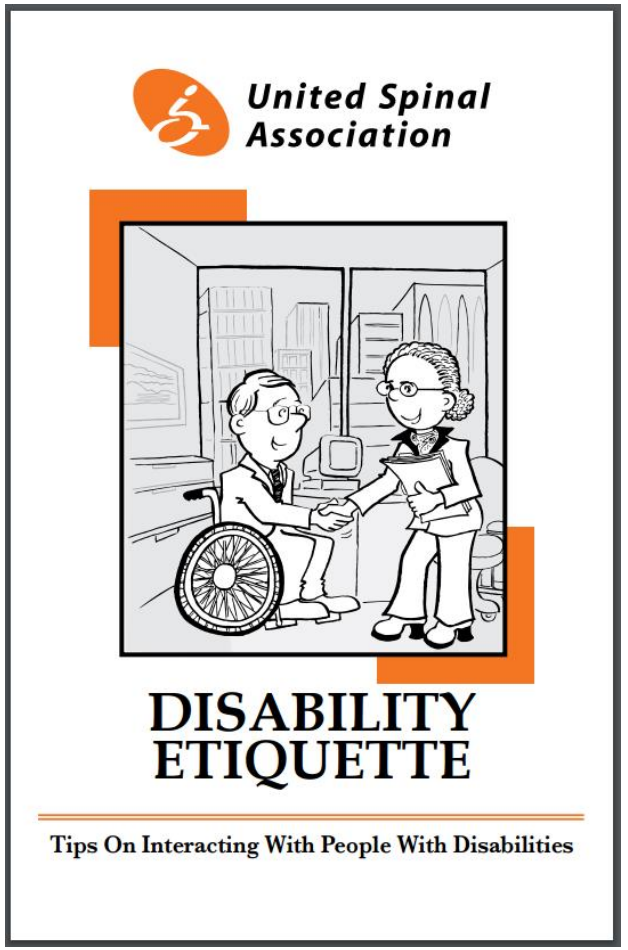
Each entry includes a definition of the word or term, a summary of how it is used or viewed by disability groups and guidance, when available, from The Associated Press Stylebook. Finally, each entry includes the NCDJ recommendation, which strives for accuracy and aims to strike a balance between clarity and sensitivity.

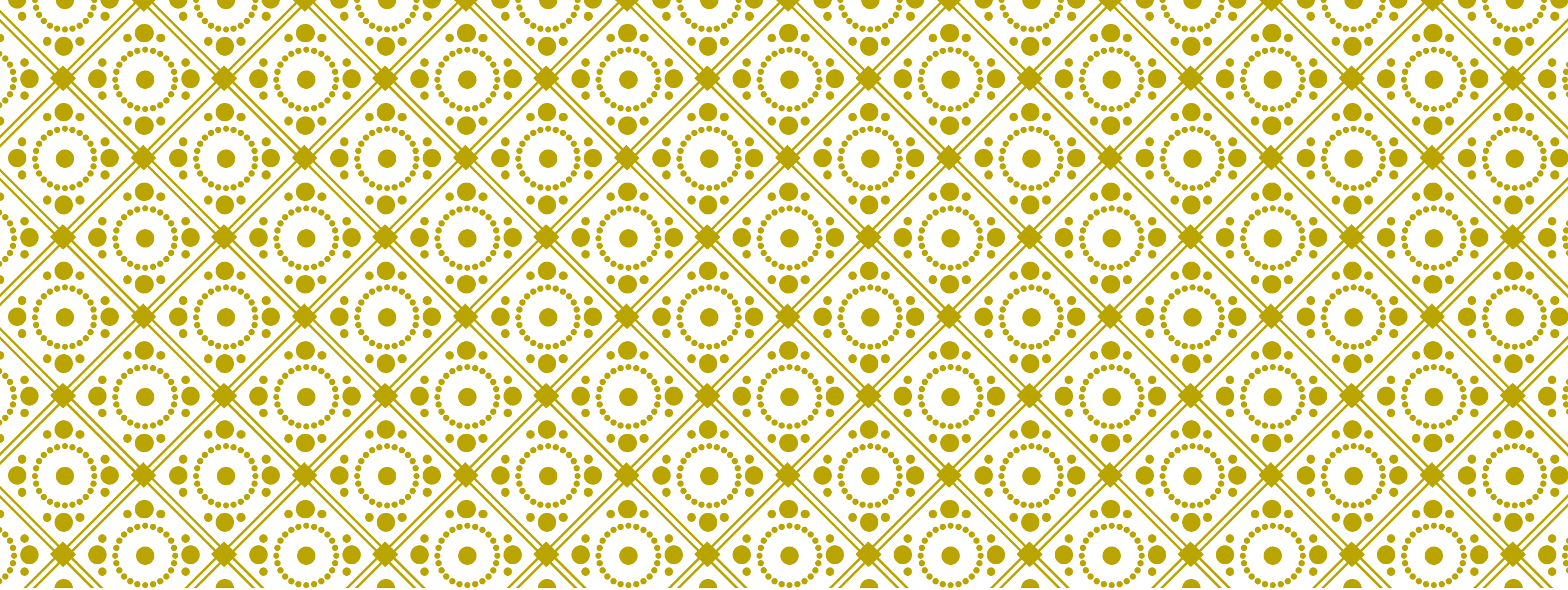
You can also **download a printable PDF of this guide by clicking here** .

See also: "Terms To Avoid When Writing About Disability"

Able-bodied

DISABILITY ETIQUETTE- TIPS





PROGRAMS AND SERVICES

ideas for libraries

PROGRAM/SERVICE IDEAS

- Medical issues specific to specific developmental disabilities
- Mental health, dental health
- Exercise and nutrition
- Parenting
- Education
- Transitioning to adulthood
- Sexuality
- Clinical trials
- Medicaid waiver, insurance, and power of attorney, guardianship
- Caretaker care, family care, sibling care
- Programs focused on specific awareness months

You don't have to be the expert!

Collaborate!

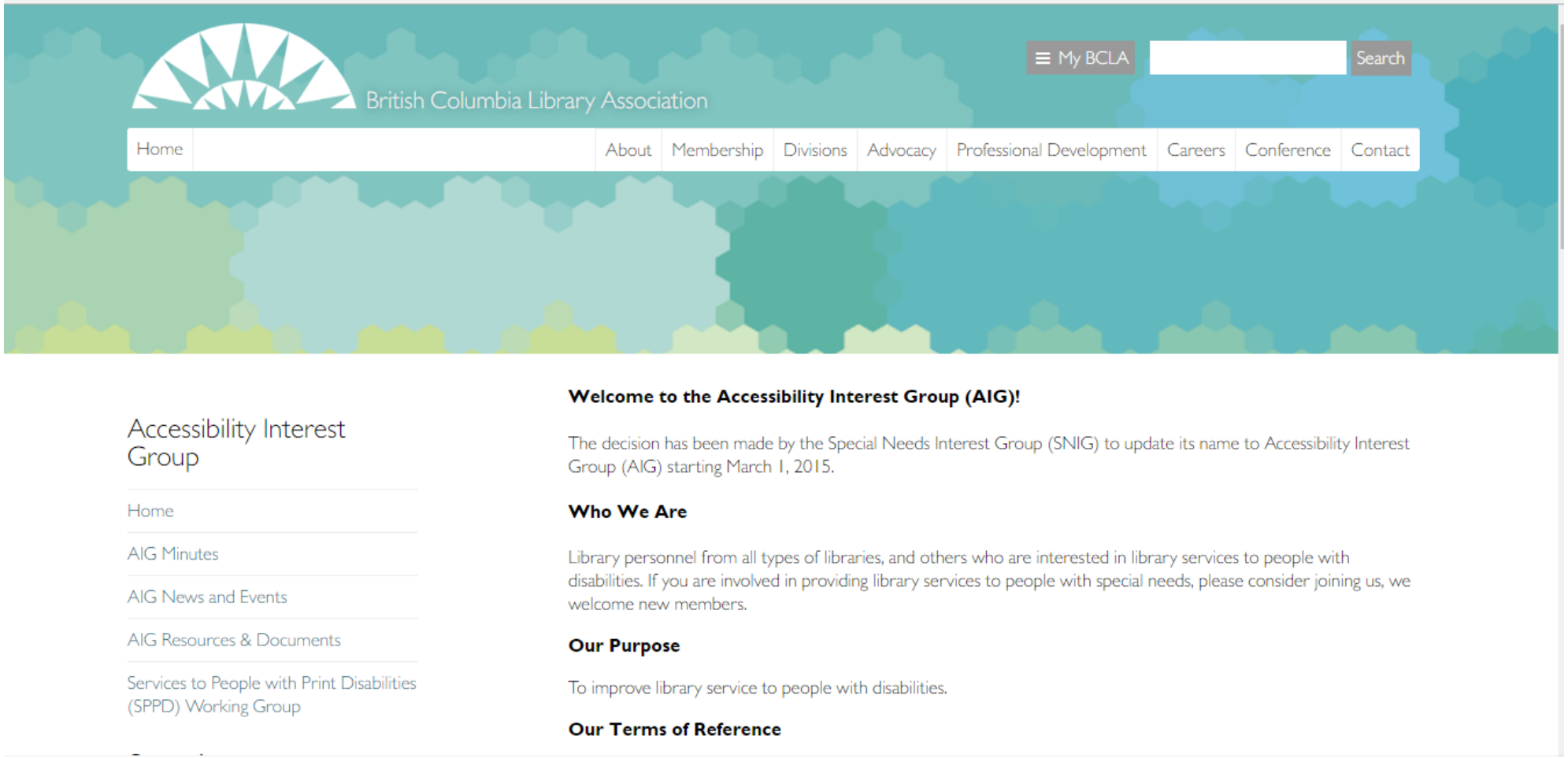
LOCATION CONSIDERATIONS

- Visible location
- Parking
- Ground level and/or elevators
- Location accessibility, ADA compliant
- Near public transportation
- Consider a separate supervised area for kids
- Be aware of visual, hearing, mobility needs
- Computers / Internet access needed?

OTHER FACTORS TO CONSIDER

- Cultural / religious sensitivity
- Health literacy: use plain language, don't rush
- Sensitive to time, may need to have very short session with most important information first
- Translators needed?
- Enough staff?
- Offer sessions to accommodate various work shifts
- Provide basic handouts
- Offer to be available after the session for specific questions
- Not too much information

ACCESSIBILITY INTEREST GROUP (AIG)



QUESTIONS

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